PERSON-CENTRED GOAL SETTING FOR EXERCISE AFTER STROKE

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ABSTRACT

Clinical guidelines and policies recommend exercise after stroke. Person-centred goal setting may facilitate the uptake and maintenance of physical activity. The aim of this work was to design and evaluate a goal setting intervention in an exercise after stroke setting. Five interlinked studies were undertaken within the development and feasibility stages of the MRC framework of complex interventions.

A systematic review examined 17 observational studies (11 quantitative, six qualitative) for the effects and experiences of goal setting in stroke rehabilitation (study one). Despite some positive effects, no firm conclusion could be reached regarding its effectiveness. Patients and professionals differed in their experiences. Barriers to goal setting outnumbered facilitators. The lack of a standardised goal setting method in stroke rehabilitation was highlighted. A goal setting intervention tailored to exercise after stroke was developed in study two, based on: findings from study one, Bandura's Social Cognitive Theory and the Canadian Occupational Performance Measure. The intervention components were: dedicated time, patient education, patient involvement, regular follow-up, and a purpose-designed workbook. This intervention was piloted in study three alongside validation of the activPAL™ activity monitor with 12 stroke survivors. The intervention did not require modification. Only two variables of the activPAL™ (time spent in sitting and upright) had acceptable validity and reliability. Feasibility of the intervention and users' experiences were investigated in study four with four stroke survivors, using mixed methods case studies. Intervention delivery and compliance were acceptable with no adverse effects. Findings regarding acceptability and content suggested a need for further work. Participants' interest and engagement in goal setting were influenced by their familiarity with goal setting, interest in physical activity, functional ability and levels of self-efficacy, highlighting the individualisation required within goal setting. Experiences of exercise professionals involved in exercise after stroke regarding goal setting were explored in study five through three focus groups (n=6; n=6; n=3). Although goal setting was viewed positively, participants felt that its potential effectiveness was not always translated into practice due to barriers encountered: clients' readiness to change, professionals' lack of knowledge about stroke and a number of organisational factors. Suggestions to improve goal setting in practice were discussed.

This work has enhanced our understanding of goal setting as a complex intervention. Recognition of the potential benefits of goal setting by both service users and providers, amidst the challenges, argues in favour of goal setting in the exercise after stroke setting. Areas for further research have been discussed.

KEYWORDS:
Stroke, goal setting, physical activity, exercise.

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10MWT	10 metre walk test
ACSM	American College of Sports Medicine
ADL	Activities of Daily Living
CMOP	Canadian Model of Occupational Performance
COPM	Canadian Occupational Performance Measure
COPM-P	Canadian Occupational Performance Measure - Performance
COPM-S	Canadian Occupational Performance Measure - Satisfaction
CT	Computed Tomography
DALYs	Disability Adjusted Life Years
EaS	Exercise after Stroke
EPHPP	Effective Public Health Practice Project
FAST	Face Arm Speech Test
FG	Focus Group
GAS	Goal Attainment Scaling
GEI	Group Exercise Instructors
GMT	Goal Management Training
GP	General Practitioner
HCP	Health Care Professional
IADL	Instrumental Activities of Daily Living
ICC	Intraclass correlation
ICF	International Classification of Functioning, Disability and Health
IPA	Interpretative Phenomenological Analysis
LLOA	Lower Limits of Agreement
LOA	Limits of Agreement
MCID	Minimally Clinically Important Difference
MCN	Managed Clinical Networks

MDC	Minimal Detectable Change
MOST	Moving On after STroke
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NHS	National Health Service
NICE	National Institute of Clinical Excellence
OT	Occupational Therapist
PC	Personal Computer
PE	Percentage Error
QMU	Queen Margaret University
RCT	Randomised Controlled Trial
REPs	Register for Exercise Professionals
ROSIER	Recognition of Stroke in the Emergency Room
RSA	Referral Scheme Advisors
SAH	Sub-arachnoid haemorrhage
SCT	Social Cognitive Theory
SEM	Standard Error of Measurement
SIGN	Scottish Intercollegiate Guidelines Network
SIS	Stroke Impact Scale
SSEQ	Stroke Self-efficacy Questionnaire
STARTER	STroke: A Randomized Trial of Exercise or Relaxation
TBI	Traumatic Brain Injury
TTM	Transtheoretical model
TUG test	Timed Up and Go test
UK	United Kingdom
ULOA	Upper Limits of Agreement
WHO	World Health Organisation

LIST OF PUBLICATIONS

1. SUGAVANAM, T., MEAD, G., DONAGHY, M., BULLEY, C., MACMILLAN, F. and VAN WIJCK, F. Accuracy of the activPAL™ monitor for use in stroke survivors. *International Journal of Stroke*. December, vol. 8, suppl. 3, p. 22.

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1. **INTRODUCTION**

The World Health Organisation (WHO) defines stroke or cerebrovascular accident as "rapidly developing clinical signs of focal (at times global (i.e. patients in deep coma and those with subarachnoid haemorrhage)) disturbance of cerebral function, lasting more than 24 hours or leading to death with no apparent cause other than that of vascular origin" (Hatano 1976, p.541). It is the second leading cause of death and the single most common cause of severe disability in the world (WHO 2013b). An increase in the ageing population and fall in stroke case fatality has led to an increase in the number of stroke survivors. Therefore, it has become essential to address the long-term needs of stroke survivors, prompting researchers to focus on life after stroke (Brainin et al. 2011). Improving physical fitness after stroke and increasing physical activity levels are aspects of life after stroke that are receiving increasing attention (Brainin et al. 2011, Brazzelli et al. 2011). Although the evidence base for the benefits of physical fitness training is growing, research has indicated that benefits gained are not always maintained at follow-up (Brazzelli et al. 2011). Behaviour change interventions have been recommended to promote maintenance of physical activity behaviour (Hillsdon et al. 2005, Biddle and Mutrie 2008, Locke and Latham 2002). One such behaviour change intervention, i.e. goal setting, is the focus of the current programme of work represented in this thesis. The aims of this work were to investigate the field of goal setting for exercise after stroke, and design and evaluate an evidence- and theory- based goal setting intervention to facilitate uptake and maintenance of physical activity after stroke. In order to address the above aims, five interlinked studies were conducted.

The organisation of this thesis is outlined below:

Chapter two

This chapter provides the background and sets the context for this programme of work. A brief overview of stroke is provided first. Important constructs such as physical

fitness, physical activity, and physical fitness training are defined and key literature relating to these constructs is critically analysed. Goal setting is then introduced as a complex intervention. Gaps in the literature are identified and the rationale for this work is outlined.

Chapter three

The overall aims of this programme of work, and the rationale and aims of the individual studies are presented.

Chapters four to eight

The five interlinked studies that were undertaken as part of this programme of work are presented as five individual chapters in the following order:

Chapter four

The systematic review conducted as study one of this work is presented in this chapter. The aim of the systematic review was to synthesise and critically analyse the evidence for the effectiveness and experiences of goal setting in stroke rehabilitation.

Chapter five

Based on the findings from the systematic review (study one, chapter four), a goal setting intervention specifically tailored for exercise after stroke was developed. The intervention development was study two of this programme of work and is presented as chapter five.

Chapter six

Study three of this work is presented in this chapter. The aim of this study was to pilot test the goal setting intervention designed in study two, familiarise with the application of the outcome measures and validate the primary outcome measure required for evaluation of the goal setting intervention.

Chapter seven

The fourth study of this programme of work was undertaken to investigate the feasibility of the above pilot tested goal setting intervention using the outcome measures validated in study three, and is presented in this chapter. The users' experiences of the intervention were also explored within this study.

Chapter eight

The fifth study of this work is presented in this chapter. The aim of this study was to explore the experiences of service providers (i.e. exercise professionals) involved in exercise after stroke regarding goal setting.

In each of these chapters, the rationale for the study, the aims, and the methods adopted are presented, followed by the findings, which are then discussed in detail.

Chapter nine

A general discussion chapter integrates the results from the individual studies to answer the primary research questions. Contributions made to the field and the implications for research and practice are also presented.

Chapter ten

The conclusion provides an overall summary of the work undertaken and the conclusions reached.

2. **BACKGROUND**

This chapter introduces the background and rationale for the programme of work. The first section provides a short overview of stroke, highlighting the problem of reduced physical fitness after stroke. The next section concentrates on physical fitness after stroke and physical fitness training, and the evidence for physical fitness training. The translation of research into practice as an exercise after stroke service and its connection with the current programme of work follows. The next section explores the barriers to exercise and methods to overcome these using long-term behavioural change interventions. One such method, goal setting, is introduced along with a discussion of the evidence for goal setting in stroke rehabilitation. A detailed explanation of the theories underpinning goal setting follows. Goal setting is then presented as a complex intervention, introducing the Medical Research Council Framework (MRC) for the design and evaluation of complex interventions. This is followed by the identification of outcome measures required for this work. Finally, the rationale for this programme of work is presented, culminating in the aims.

2.1. **Stroke: an overview**

2.1.1. **Definition and classification of stroke**

The definition of stroke by the WHO is presented in chapter 1. There are two main types of stroke: ischaemic stroke and haemorrhagic stroke. Ischaemic stroke accounts for nearly 80% of all stroke cases. It is caused by an inadequate cerebral blood supply to a part of the brain as a result of low blood flow; or thrombosis or embolism associated with diseases of the blood vessels (arteries or veins), heart or blood (Warlow et al. 2008). A spontaneous haemorrhage into the brain substance caused by bleeding of a blood vessel supplying the brain is termed a haemorrhagic stroke (Mant 2011). Sub arachnoid haemorrhage (SAH) is where bleeding occurs into the subarachnoid space,

usually as a result of the rupturing of an aneurysm. Along with other symptoms, SAH can produce focal symptoms of a stroke (Mant 2011).

2.1.2. **Incidence, prevalence and impact of stroke**

2.1.2.1. Incidence of stroke

Stroke is a disease that can occur at any age. The incidence (i.e. the number of new cases) rises sharply with age and predominantly occurs in mid-age and older adults (Mant 2011). Stroke is reported to occur 30% more often in men than women. This difference tends to decrease with age. However, strokes are more severe in women and cause a slightly greater percentage of deaths when compared to men (Appelros et al. 2009).

The incidence of stroke is on the decline in developed countries, due to better risk prevention methods (WHO 2013a). In the United Kingdom (UK) alone, stroke incidence has fallen by 30% between 1999 and 2008 (Lee et al. 2011). The Information Services Division (2014) has reported that the incidence rate of stroke decreased in Scotland by 21% in the past decade (from 194.1 cases per 100,000 population in 2003/04 to 153.7 cases per 100,000 population in 2012/13).

Similarly, mortality due to stroke is continuing to fall in developed countries (WHO 2013a). In Scotland, there has been a reduction in the mortality rate of stroke from 79.3 per 100,000 population in 2003 to 45.6 per 100,000 population in 2012, an overall reduction of 42.5% (Information Services Division 2014).

2.1.2.2. Prevalence of stroke

Although the incidence and mortality of stroke are decreasing, the prevalence of stroke continues to rise globally, due to an increase in the ageing population (WHO 2013a). In

the UK, it has been reported that the number of people aged 65 and over increased by 20% between 1985 and 2010, while the number of people aged 85 and over doubled over this period (UK National Statistics 2012). It has also been projected that this increase in the ageing population will continue over the years to come. In the UK, it has been estimated that by 2035, people aged 65 and over will account for 23% of the total population, while people aged 85 and over will account for 5% of the total population, which is 2.5 times more than in 2010 (UK National Statistics 2012). With this increase in the ageing population and the fall in stroke case fatality, more people are surviving a stroke but are left with disabilities. Therefore, stroke continues to be a major health problem.

2.1.2.3. Impact of stroke

Stroke is the second leading cause of death and the single most common cause of severe disability in the world (WHO 2013b). It is estimated that annually 15 million people worldwide suffer a stroke, of whom 5 million die and another 5 million are left permanently disabled (WHO 2013a). The disability caused by stroke places a great social and economic burden on the family and the community. This stroke burden is projected to rise from around 38 million Disability Adjusted Life Years (DALYs) globally in 1990, to 61 million DALYs in 2020 (WHO 2013a).

In the UK, stroke is the biggest single cause of major disability (WHO 2013a). It has been estimated that the total cost of stroke to the UK is around £9 billion per year, with the National Health Service (NHS) costs alone estimated to be around £4.4 billion per year (Saka et al. 2009). Informal care for stroke survivors, and indirect costs associated with productivity and disability, has been estimated to be around £2.5 billion and £1.5 billion per year respectively (Saka et al. 2009).

In Scotland stroke is the third most common cause of death and the most common cause of severe physical disability amongst adults. It is estimated that about 15,000 people in Scotland have a stroke each year. The cost of acute medical services for stroke patients in Scotland is at least £100 million per year and the economic cost in terms of lost employment and independence is significant, whilst the impact on family members, or friends who care for stroke survivors, is considerable (Information Services Division 2014).

2.1.3. **Main clinical features**

The manifestations of stroke depend on the side and region of the brain affected. Accordingly, domains of sensation, perception, motor function, cognition, speech and language, emotion and/or motivation could be affected. Some of the presenting features include: hemiplegia/hemiparesis, hemisensory loss, sensory and visual inattention, dysphasia (expressive and/or receptive), neglect, ataxia, facial palsy, dysphagia, and dysarthria (Markus, 2004). Complications after stroke are common and they include: recurrent stroke, epileptic seizures, infections, pain, falls, depression, anxiety and social isolation (Gordon and Jenkinson, 2011).

2.1.4. **Diagnosis of stroke**

Stroke is a clinical diagnosis. To screen for a diagnosis of stroke outside the hospital setting in people with sudden onset of neurological symptoms, a validated tool, such as the Face Arm Speech Test (FAST) is used. In accident and emergency centres, a validated tool such as Recognition of Stroke in the Emergency Room (ROSIER) has been recommended (NICE 2008). Brain imaging is conducted to distinguish between an ischaemic and haemorrhagic stroke, and plan management accordingly (NICE 2008). A computed tomography (CT) scan is done in most cases, while some patients undergo a magnetic resonance imaging (MRI) (Mead and Dennis 2013).

2.1.5. **Management of stroke**

Management of stroke in the UK is based on guidelines put forth by the Intercollegiate Stroke Working Party (2012), and the National Institute for Health and Clinical Excellence (NICE) (2008, 2013) with Scotland following the guidelines put forth by the Scottish Intercollegiate Guidelines Network (SIGN) (2010, 2008). The management of stroke can be traced along the stroke pathway as specified in these guidelines, which include acute management, rehabilitation, secondary prevention, and life after stroke. These are discussed below.

2.1.5.1. Acute management

Acute management of stroke includes confirmation of the diagnosis using brain imaging, thrombolysis treatment where appropriate, admission to a specialist stroke care unit, and general supportive care. For all types of stroke, admission to a stroke unit is strongly recommended (NICE 2008, Intercollegiate Stroke Working Party 2012, SIGN 2010). Dedicated stroke units have demonstrated improved outcomes in terms of multidisciplinary team care, early mobilisation, involvement of patients and carers in all aspects of care, reduction in the number of complications, and long term reductions in death, dependency, and the need for institutional care (Langhorne 1997, Indredavik et al. 1999). In ischaemic stroke cases, patients are treated with aspirin, and for suitable cases, thrombolysis is carried out. Drugs which increase the risk of bleeding are stopped after a haemorrhagic stroke. Surgical removal of the blood clot and bleeding are undertaken in some cases (Intercollegiate Stroke Working Party 2012, SIGN 2010).

2.1.5.2. Rehabilitation

Clinical guidelines recommend that whenever possible, patients with stroke are rehabilitated in a specialist stroke rehabilitation unit (Intercollegiate Stroke Working

Party 2012, NICE 2013, SIGN 2010). Rehabilitation is an essential part of stroke recovery for a considerable proportion of stroke survivors and starts from the acute stage of stroke irrespective of the severity of the stroke. The main aims of rehabilitation are to reduce impairments caused by stroke, and to promote physical and psychosocial recovery, concentrating not only on the short-term, but also on long-term recovery (Walker 2011). A multi-disciplinary team is usually involved in the care of the patient (Mead and Dennis 2013, Walker 2011). The members of the team usually include doctors, nurses, physiotherapists, occupational therapists, dieticians, speech and language therapists, social workers, psychologists, orthotists, and pharmacists. Rehabilitation started in the inpatient setting may be continued as community rehabilitation according to the requirements of the individual. To reduce inpatient stay and to improve service provision in the community, early supported discharge schemes with a multi-disciplinary team in the community have been trialled (Langhorne et al. 2007), and based on the effectiveness, are currently recommended in UK and Scottish clinical guidelines (Intercollegiate Stroke Working Party 2012, SIGN 2010).

2.1.5.3. Secondary prevention

Early secondary prevention measures are considered critical to reduce the risk of further strokes (SIGN 2010). Advice on lifestyle modifications and blood pressure lowering methods are the key secondary prevention measures (Mead and Dennis 2013). Lifestyle modification advice includes smoking cessation, reduction of alcohol consumption, weight reduction (if overweight), salt intake reduction, and increased physical activity levels (Mead and Dennis 2013).

2.1.5.4. Life after stroke

Most of the rehabilitation services offered in the UK are restricted to the first year after stroke due to the limited services available. Therefore, to a large extent, post-discharge

recovery lies within the hands of the individual and their carers (Walker 2011). The NHS, voluntary organisations such as Chest Heart and Stroke Scotland (http://www.chss.org.uk/stroke/) and the Stroke Association (http://www.stroke.org.uk/), and some community centres offer a range of services to aid recovery. The services offered not only support the rehabilitation process, but also promote 'life after stroke'. Self-management, community integration, social inclusion, maintaining gained effects, increasing levels of physical activity, return to work and return to leisure activities form the major focus at this stage (Walker 2011, NHS Improvement 2008). Along with other services, participating in community exercise and fitness classes to improve physical fitness has been recommended as part of 'life after stroke' (Department of Health/Vascular Programme/Stroke 2007).

As explained in section 2.1.2.2, the increase in the ageing population and fall in stroke case fatality have led to an increase in the number of stroke survivors. Therefore, it has become essential to address the long-term needs of stroke survivors. This has prompted researchers to focus on life after stroke (Brainin et al. 2011). Improving physical fitness after stroke and increasing physical activity levels are aspects of life after stroke that are increasingly gaining attention. This is discussed in detail in the following sections.

2.2. **Physical fitness and physical activity/inactivity after stroke**

2.2.1. **Definition**

Physical fitness is defined as "a set of attributes that people have or achieve that relates to the ability to perform physical activity" (Caspersen et al. 1985, p.129). Physical activity is defined as "any bodily movement produced by skeletal muscles that result in energy expenditure" (Caspersen et al. 1985, p.129). Exercise has been identified as a sub-category of physical activity and is defined as "planned, structured, and repetitive

bodily movement done to improve or maintain one or more components of physical fitness" (Caspersen et al. 1985, p.129).

2.2.2. **Components of physical fitness**

According to the American College of Sports Medicine (ACSM), physical fitness comprises five health-related components, namely: cardio-respiratory fitness (or aerobic fitness), muscular endurance, muscular strength, body composition, and flexibility (ACSM 2014). The definitions of these terms are presented in Table 2.1

Table 2.1: Definitions of the main components of physical fitness

(Caspersen et al. 1985, p.129)

Cardio-respiratory fitness	"A health-related component of physical fitness that relates to the ability of the circulatory and respiratory systems to supply fuel during sustained physical activity and to eliminate fatigue products after supplying fuel."
Muscular endurance	"A health-related component of physical fitness that relates to the ability of muscle groups to exert external forces for many repetitions or successive exertions."
Muscular strength	"A health-related component of physical fitness that relates to the amount of external force that a muscle can exert."
Body composition	"A health-related component of physical fitness that relates to the relative amounts of muscle, fat, bone, and other vital parts of the body."
Flexibility	"A health-related component of physical fitness that relates to the range of motion available at a joint."

All or some components of physical fitness may be compromised in an individual affected by stroke due to the factors discussed in the next section.

2.2.3. **Physical fitness after stroke**

Physical fitness is reduced after stroke and this may affect the performance of every day activities. Various factors contribute to this reduced physical fitness. Saunders and Greig (2013) have summarised the reasons into the following three broad categories.

2.2.3.1. Indirect pre-stroke factors

The normal ageing process causes a decline in cardio-respiratory fitness and muscle strength. This, along with any other co-existing physical disease and other risk factors such as sedentary behaviour and smoking, can reduce physical fitness in the ageing population even before the incidence of stroke (Saunders et al. 2009, Skelton et al. 1999). This is of importance, as most strokes occur in the elderly.

2.2.3.2. Direct effects of stroke

The direct effects of stroke on physical fitness can be analysed by considering its effects on the main components of physical fitness.

2.2.3.2.1. Cardio-respiratory fitness

Smith et al. (2012) identified peak oxygen uptake of stroke patients through a systematic review of 41 studies (n=1569) and compared these values with published data from age and gender-matched controls. The authors estimated that the VO_2 peak of stroke patients is around 26-87% of that of healthy age- and gender-matched individuals. However, as the authors acknowledge, most of the studies had included only people with mild

strokes. Therefore, it is not known if patients with severe stroke would be able to complete the peak oxygen uptake measurement test and if so, how those values would compare with age- and gender-matched controls. Nevertheless, this review highlighted that the cardiorespiratory fitness of stroke patients is lower than healthy counterparts.

It has also been demonstrated that the metabolic cost of walking in people with stroke is considerably higher than that of age-matched controls, even after the confounding variable of low gait speed was controlled for (Da Cunha Jr et al. 2002, David et al. 2006, Platts et al. 2006). This means that although people with stroke walk at a low speed, they consume the same amount of oxygen as their healthy counterparts who walk twice as fast, implying that hemiplegic gait is energetically inefficient (Waters and Mulroy 1999). This can make the performance of activities of daily living (ADL) arduous, leaving the stroke survivor with very little reserve energy left for any further physical activity (Gordon et al. 2004).

2.2.3.2.2. Muscular strength and endurance

As mentioned earlier (section 2.1.3), hemiplegia or hemiparesis (i.e. loss or weakness of voluntary movement in upper and lower limbs on the side contralateral to the brain lesion) is one of the common manifestations of stroke. Suresh et al. (2011) propose three mechanisms that could contribute to this weakness: muscle fibre atrophy and contracture; changes in the spatial and/or temporal patterns of muscle activation; and disorganisation of motor unit recruitment and rate modulation patterns. Evidence has shown that in stroke survivors, muscle strength and endurance of most of the muscle groups are reduced in both the paretic and non-paretic side (Andrews and Bohannon 2000, Bohannon and Andrews 1995, Saunders et al. 2008, Ng and Hui-Chan 2005). For example, in a retrospective study of 48 stroke patients, the strength of most muscle groups of the paretic side was reduced to about 20%-45% of normal, while those on the non-paretic side were reduced to about 70%-80% of normal (Andrews and Bohannon

2000). The non-paretic side could be involved directly due to the stroke affecting the ipsilateral pathways, or indirectly due to the pre-stroke factors (mentioned earlier) and/or post stroke factors which are described in the next section (Andrews and Bohannon 2000, Saunders et al. 2008).

2.2.3.3. Indirect post-stroke factors

Co-morbid conditions such as coronary heart disease have also been demonstrated to influence the physical fitness levels of stroke patients (MacKay-Lyons and Makrides 2002). Post-stroke physical inactivity is believed to further reduce the physical fitness of stroke patients (Saunders and Greig 2013). This is discussed in detail in the next section.

2.2.4. Physical activity levels after stroke

Physical activity levels have been demonstrated to be low post-stroke, both in hospitalised stroke patients and community-dwelling stroke survivors (Field et al. 2013, West and Bernhardt 2012).

A recent systematic review of 24 observational studies with hospitalised stroke patients reported that nearly 48.1% of a typical day was spent inactive (i.e. nil physical activity) (West and Bernhardt 2012). However, the wide range (24.2% to 98.0%) observed for this measure should be taken into consideration when interpreting the results The review also reported that 27.5% of the day was spent in low physical activity (this included sitting supported out of bed and self-care), while 21% of the day was spent in moderate to high physical activity (moderate physical activity included sitting unsupported and transferring without hoist equipment; high physical activity included activities involving standing and walking) (West and Bernhardt 2012). It should be noted that the definition of the nil, low, moderate and high physical activity do not relate to the intensity of the activity performed. The activities were recorded in most of the included studies by

behavioural mapping (i.e. structured observation). No objective measurements such as accelerometers were used in any of the included studies. The sample size could not be identified as the total numbers of participants involved in each study were not presented. Interestingly, this review identified that although the stroke patients spent approximately one hour each in formal Physiotherapy and Occupational Therapy sessions, only limited time within this could be classed as moderate to high physical activity. However, this varied between studies and therefore no median percentages were provided for this (West and Bernhardt 2012). The authors, however, had included participation in formal therapy sessions under the moderate to high level of activity, and it is not clear if the periods of inactivity within the formal sessions were accounted for in the overall classification of the activities. If these were not accounted for, then the percentage of time spent in moderate to high physical activity could have been overestimated. The activity levels were reported to be even lower for patients within 14 days post-stroke when compared to stroke patients after this time period (West and Bernhardt 2012, Bernhardt et al. 2004). When 58 people with stroke were observed during a therapeutic day within the first 14 days of acute stroke, they spent more than 50% of the time resting in bed, 28% sitting out of bed, and only 13% of the time was spent in activities with the potential to prevent complications and improve recovery of mobility (Bernhardt et al. 2004). In another individual study not included in the above review, 41 stroke survivors were observed in a rehabilitation unit, and it emerged that they spent only an average of 8.3% of the therapeutic day upright, as measured using an instrumented recording device (Egerton et al. 2006).

Physical activity levels in stroke survivors living in the community were also low. A recent well-conducted systematic review of 26 studies (n=1105) concluded that physical activity levels in the stroke survivors were low in quantity, duration, and intensity (Field et al. 2013). In this review, the researchers conducted a meta-analysis with 11 studies (n=315) and reported a random effect summary of 4355.2 steps per day. This was identified to be well below the recommended number of steps per day in healthy elderly

individuals (6000 steps/day) (Tudor-Locke et al. 2002) and in people with chronic illness/disability (6500-8500 steps/day) (Tudor-Locke et al. 2011). The intensity of activity was also reported to be lower than the recommended levels (Field et al. 2013).

Overall, physical activity levels appear to be low after stroke. The impact of this is discussed next.

2.3. Impact of reduced physical activity and fitness after stroke

The low levels of physical activity demonstrated throughout all stages of stroke can have a profound effect on physical fitness. In turn, reduced physical fitness is often cited as a reason for the low physical activity levels after stroke (Gordon et al. 2004). Thereby a vicious cycle of physical inactivity and reduction in physical fitness is formed (Saunders and Greig 2013, Gordon et al. 2004, Carr and Shepherd 2011).

Reduced physical fitness and low physical activity levels after stroke can have an impact on all the domains in the International Classification of Functioning, Disability and Health (ICF) (Saunders and Greig 2013). As per the ICF, the domains of body functions and structures, activities, and participation are inter-related. Hence, a disturbance at any one level can cause a change in other domains as well (WHO 2001). Similarly, in stroke survivors, a reduction in any of the components of physical fitness can impact on basic functions such as walking ability and walking speed, which in turn can affect the performance of ADL (e.g. bathing, cooking) (Flansbjer et al. 2006, Ivey et al. 2006, LeBrasseur et al. 2006). This in turn can have a direct effect on the individual's fulfilment of family and social roles. Low physical fitness after stroke can also affect the general health of a person by increasing the risk of falls and secondary cardiac complications (Gordon et al. 2004).

Most of the above stated problems can be influenced by physical fitness training or exercise training as discussed below.

2.4. **Physical fitness training**

Physical fitness training or exercise training that improves either cardio-respiratory fitness, or strength and muscular endurance, or both, have been advocated to overcome reduced physical fitness after stroke (Saunders and Mead 2013). 'Physical fitness training' (or exercise training) is "a planned, structured, repetitive regimen of regular physical exercise deliberately performed to improve one or more components of physical fitness" (US Department of Health and Human Services 1996, p. 20).

2.4.1. **Evidence for physical fitness training in stroke**

A recent Cochrane systematic review included 32 randomised controlled trials (RCTs) with a total of 1414 participants with stroke to evaluate the evidence for the effectiveness of physical fitness training for stroke (Brazzelli et al. 2011). This systematic review was the third update of a previously published systematic review. The original review included only 12 studies (Saunders et al. 2004), while in the next update the number of included trials increased to 24 (Saunders et al. 2009). This increase in the number of studies included indicates clearly that physical fitness training is gaining importance in stroke rehabilitation. Brazzelli et al. (2011) concluded that cardio-respiratory training involving walking can improve walking speed, tolerance, and independence. A more tentative conclusion was arrived at in relation to the effects of resistance training on improving muscle strength. However, no firm conclusions were reached regarding the effects of physical fitness training on death, dependence, and disability after stroke. Most of the included studies had only recruited stroke survivors who were able to walk at least a few metres, which may not be a valid representation of the stroke population; this should be considered when using this evidence to prescribe

exercise training. Of the 32 included trials, only 13 had conducted follow-up assessments, which varied from six weeks to nine months after completion of the training. The effects of cardio-respiratory training on walking speed and walking capacity were retained at follow-up. However, this was based on only three studies (Mudge et al. 2009, Bateman et al. 2001, Eich et al. 2004). For all other variable, effects gained at the end of the intervention appeared to have been lost at follow-up. Therefore, the authors recommended further research to evaluate long-term benefits of training. The type, duration and frequency of training varied widely, prompting more research to identify optimal training parameters. Overall, exercise training appeared to be safe and feasible in this population (Brazzelli et al. 2011).

Research has highlighted that exercise training not only results in physical benefits, but can also bring about psychosocial benefits (Carin-Levy et al. 2009, Reed et al. 2010, Sharma et al. 2012). Stroke survivors who attended exercise classes reported improvements in mood, self-efficacy, and self-perception of quality of life. They also perceived that the training helped them to gain control of their lives and facilitated self-management (Carin-Levy et al. 2009, Reed et al. 2010, Sharma et al. 2012). However, it should be noted that one half of the participants in the study of Carin-Levy et al. (2009) had participated only in relaxation classes and not exercise classes. Therefore, the benefits could not be attributed to the exercise training alone. The review of Brazzelli et al. (2011) included outcome measures of quality of life and mood. Due to the small number of trials evaluating these outcomes, and inconsistent results, no firm conclusions could be reached in relation to the effects of physical fitness training on quality of life and mood. However, some positive effects were apparent for quality of life. Overall, the evidence base regarding the psychosocial benefits of exercise training, although positive, appears to be a relatively new area requiring further research to improve the evidence-base.

2.4.2. **Current policies and guidelines**

Based on the evidence summarised above, recommendations to provide physical fitness / exercise training after stroke have been included in current policies and guidelines globally (Intercollegiate Stroke Working Party 2012, NICE 2013, SIGN 2010, National Stroke Foundation 2010, Lindsay et al. 2010). These guidelines and policies emphasise that stroke survivors should be involved in physical fitness training and that these services should be available in the community. Some of the relevant extracts from the guidelines published in the UK are presented in Table 2.2.

Table 2.2: Extracts from guidelines recommending physical fitness training after stroke

Guideline reference	Relevant extracts
National Stroke Strategy (Department of Health/Vascular Programme/Stroke 2007, p.38)	"Rehabilitation – support to regain well-being – requires rehabilitation specialists and continuing support from a wide range of community-based services, such as exercise classes, communication support groups, accessible further education and employment opportunities, arts and leisure activities, self-management activities and self-help groups, offered by appropriately trained and supported statutory and voluntary agencies."
National Clinical Guideline for stroke (Intercollegiate Stroke Working Party 2012, p.83)	"After stroke, patients should participate in exercise with the aim of improving aerobic fitness and/or muscle strength unless there are contraindications."
SIGN guideline 108 (SIGN 2008, p.49)	"Life-long participation in programmes of exercise after stroke should be encouraged".

SIGN guideline 118 (SIGN 2010, p.17 and p.54)	"Gait-oriented physical fitness training should be offered to all patients assessed as medically stable and functionally safe to participate, when the goal of treatment is to improve functional ambulation." "The guidelines recommend that services need to be available in the community to encourage people with stroke to engage in physical activity."
Better Heart Disease and Stroke Care Action Plan (Donnelley 2009, p.72)	"NHS Boards, through their stroke Managed Clinical Networks (MCNs), should continue to work with leisure industry representatives to make best use of this new training course to improve access to exercise and fitness training for people with stroke in their area."

2.4.3. **Translating research into practice**

The growing evidence for benefits of physical fitness training after stroke and related recommendations in clinical guidelines has supported the development of Exercise after Stroke (EaS) services in the community. A best practice guidance document for the development of EaS services in community settings has also been published (Best et al. 2010). In a study investigating the appropriateness and acceptability of exercise on prescription schemes for stroke survivors, it was highlighted that fitness instructors' low levels of knowledge about stroke raises issues of safety for the stroke survivors (Wiles et al. 2008). Although this was a small study conducted within the South of England, the concerns raised were valid. In line with this, a Specialist Instructor Training course for exercise instructors and suitably qualified professionals was developed in 2007 to enable exercise instructors to design and deliver exercise programmes safely and effectively for stroke survivors (www.exerciseafterstroke.org.uk). It was validated and delivered through Queen Margaret University (QMU), Edinburgh, UK for the first three years and then licensed to Later Life Training (www.laterlifetraining.co.uk).

As part of developing recommendations for best practice and promoting EaS service development, a survey was conducted in Scotland in 2009. Data collected included: number of EaS services in the region, its distribution, content of exercise session, referral and assessment processes, and the qualifications of Exercise Instructors (Best et al. 2012). A total of 14 EaS services were identified through this survey, of which seven of these were run by charitable organisations, four by leisure centres, and three by health services (Best et al. 2012). Based on the total number of stroke survivors in the region, the authors concluded that there were not enough EaS services to accommodate the demand. Data from other regions of the UK are not available, and therefore no further comparisons could be made on the number of services. Although the authors were fairly confident that all the services were identified through the survey and follow-ups, the 36% of non-responders cannot be overlooked.

One EaS service is discussed in more detail next, along with its relevance to this programme of work.

2.5. **Exercise after Stroke Service**

The current programme of work was conducted in collaboration with an EaS service established in one city of Scotland. The content of the exercise program provided in this service is based on a RCT by Mead et al. (2007) called Stroke: A Randomized Trial of Exercise or Relaxation (STARTER). It is a combination of aerobic, resistance and endurance training and is specifically designed for stroke survivors; it has been shown to be safe, effective and feasible (Mead et al. 2007). The service was launched in September 2008 and was updated in August 2011. In the updated programme, the classes are delivered as one-to-one sessions, circuit sessions, and mainstream exercise.

One-to-one sessions are designed for stroke survivors who present with communication, cognitive, visual, or physical (requiring assistance to access equipment) problems. These sessions are delivered by qualified exercise instructors (Register for Exercise Professionals (REPs) Level 4) who have completed the aforementioned Exercise after Stroke Specialist Instructor Training Course. The circuit sessions are designed for more able stroke survivors (both physically and mentally), who still require some supervision while exercising. These sessions are delivered in small groups by Exercise Referral Specialists (Level 3) who have had additional training and guidance in stroke awareness. The mainstream exercises are suitable for stroke survivors who would be able to follow an individual gym programme (developed by a specialist instructor) independently without support. Participants are reassessed every 12 weeks, and once fit enough to continue exercising on their own, they are discharged from the service with encouragement to independently continue exercising.

This EaS service is an exercise on referral scheme; hence participants must have been referred through an appropriate health care professional (e.g. stroke specialist health professional) in accordance with the Department of Health's guidance for exercise referral schemes (Department of Health 2007). The criteria for referring participants to this EaS service are that they must: (i) have a confirmed diagnosis of stroke (ii) be motivated to participate in and likely to benefit from an exercise programme (iii) be medically stable (iv) not put themselves or others at risk by presenting themselves under the influence of alcohol or drugs and (v) be able to follow simple instructions by most appropriate method (verbal, visual cues and written).

2.6. **Barriers and motivators for exercise after stroke**

Although an increasing body of evidence demonstrates that exercise training is effective, most improvements gained tend to be lost at long-term follow-up (Brazzelli et al. 2011,

Touillet et al. 2010). Long-term engagement in physical activity is being recommended to maintain the improvements gained from exercise training and rehabilitation (Brazzelli et al. 2011). However, research has identified that the majority of stroke survivors return to a sedentary life after rehabilitation and do not meet the daily recommended physical activity levels (Ashe et al. 2007, Rand et al. 2009, Shaughnessy et al. 2006). In order to understand this behaviour in this population, researchers have explored the barriers and motivators for exercise and physical activity.

A recent systematic review of six studies with 174 stroke survivors identified that lack of motivation, environmental factors (e.g. transport), health concerns, and stroke impairments were the most commonly reported barriers for physical activity after stroke (Nicholson et al. 2013). The most commonly reported motivators were social support and the need to be able to perform daily tasks (Nicholson et al. 2013). Other barriers identified from individual studies include: low self-efficacy/confidence, lack of interest, perceived fear of consequences, post-stroke mood difficulties, lack of energy, misperceptions of the meaning of physical activity and exercise, lack of knowledge of how and where to exercise, lack of exercise options, and cost of the programme when available (Damush et al. 2007, Simpson et al. 2011, Rimmer et al. 2008). Self-motivation, extrinsic motivation from qualified personnel, exercising with peer stroke survivors, and a sense of fulfilment were some of the motivators identified in individual studies (Damush et al. 2007, Simpson et al. 2011).

Another recent systematic review of 20 studies (of which one was a RCT) conducted to identify the psychological and social factors that influence the uptake and maintenance of physical activity after stroke, concluded that self-efficacy, beliefs about physical activity, and social support are the major factors that influence physical activity behaviour after stroke (Morris et al. 2012). However, most of these studies included stroke survivors who were participating in some form of exercise classes and therefore their views may not be representative. It is more important to gather the views of

participants who drop-out of exercise classes or refuse participation in such classes, to ensure a more complete understanding. The ethical difficulties associated with collecting information from this sub-group should, however, be acknowledged. It should also be noted that of the 20 studies included in the above review, only four were conducted in the UK. This is important as health services and facilities differ between countries, and the importance of some barriers such as lack of facilities, may differ between regions.

To overcome the above stated barriers and to encourage long-term participation in physical activity, interventions promoting behaviour change have been recommended (Biddle and Mutrie 2008, Damush et al. 2007, Morris et al. 2012). Morris et al. (2012) have specifically called for theoretically based physical activity interventions to improve uptake of physical activity in stroke survivors. A comprehensive body of evidence has identified that behavioural change may be achieved through a number of strategies, including: goal setting, education, regular follow-up, regular information provision, and counselling (Hillsdon et al. 2005, Biddle and Mutrie 2008, Locke and Latham 2002). Although most of this evidence was based on healthy populations and in people with addiction problems, the use of these strategies in rehabilitation and self-management settings is on the increase (Biddle and Mutrie 2008, Stuifbergen et al. 2003, Lorig et al. 2001).

Of these strategies, goal setting is of interest and the focus of this programme of work, and is explored in detail in the following section.

2.7. **Goal setting**

As mentioned above, person-centred goal planning has been identified as a means of promoting behavioural change in both healthy and patient populations (Biddle and Mutrie 2008, Wade 1998, Levack et al. 2006a). In the following sub-sections, the

definition and background of goal setting are presented first. Then the literature on goal setting for exercise after stroke and rehabilitation is reviewed in a narrative way. The theoretical underpinnings of goal setting are presented next. Current policies and guidelines related to goal setting are then highlighted.

It should be noted that this section formed the foundation of the current programme of work, which began in September 2008. Hence the rationale for the various studies undertaken as part of this programme of work was based on literature published until the end of 2010 and only these have been used in this section. Since then, further relevant literature has been published and this is considered and discussed in the individual chapters and in the general discussion.

2.7.1. **Definition**

'Goal' is defined as "an aim or a desired target" in the Oxford English dictionary (Oxford University Press 2013), while Locke and Latham (Locke and Latham 2002, p.705) describe goal as "the object or aim of action".

Three different definitions were identified for the terms 'goal setting' and/or 'goal planning'. The Intercollegiate Stroke Working Party of the Royal College of Physicians (2008, p.37) have defined goal setting as "the identification of and agreement on a behavioural target which the patient, therapist or team will work towards over a specified period of time". It should be noted that this guideline has since been updated; however, no change has been made to the above definition (Intercollegiate Stroke Working Party 2012, p.31). Wade (1998, p.273) has defined it as "the process of agreeing on goals, this agreement usually between the patient and all other interested parties. This process might include setting goals at various levels and in various time frames." A third definition is by McGrath and Davis (1992, p. 226) who define goal

setting as “a directive activity incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation”.

The first two definitions are very similar and they highlight the idea that the patients must be included within the whole goal setting process. However, in current practice, it appears that this is not always the case (Leach et al. 2010). The definition of McGrath and Davis (1992), on the other hand, proposes goal setting as a “directive activity” and the role of the patient is not emphasised. If involvement of the patient is expected to be at the core of goal setting, then the first two definitions appear more appropriate. Therefore, the detailed definition of goal setting by the Intercollegiate Stroke Working Party (2012, 2008) is used and referred throughout this thesis, except in the systematic review presented in chapter 4. The reasons for this are explained in detail in that chapter (section 4.3).

2.7.2. **Background**

Goals and goal setting fall within the broad domain of cognitive psychology and have a long history, dating back to the 1930s (Locke and Latham 2002, Locke et al. 1981). Locke and Latham (2002) report that the effects of goals on task performance were evaluated as early as 1935 by Mace, and that Lewin and colleagues studied conscious goals in the 1940s. In the early years, goal setting was researched and used predominantly in academic and industrial organisations to improve task performance, with the theoretical belief that goals regulate and affect human action (Locke et al. 1981).

During the following years, the concept of goal setting became a central component of many theories, such as Social Cognitive Theory and Goal Setting Theory (Locke and Latham 2002, Locke et al. 1981, Bandura and Simon 1977, Gauggel and Hoop 2004). These theories and the mechanisms of goal setting will be explored in depth in section

2.7.5. The development of such theories led to goal setting being considered a key component of behaviour change interventions (Locke et al. 1981, Gauggel and Hoop 2004). These behavioural change interventions were used for the treatment of common health problems such as depression and anxiety (Davidson and Joice 2008, Ralston 2008). A need to evaluate the effectiveness of such mental health programs led to the development of the Goal Attainment Scaling (GAS) tool in the late 1960s (Kiresuk and Sherman 1968).

As GAS helped to evaluate goal attainment, this measure began to gain in popularity, and its use moved from the mental health setting to various fields, including rehabilitation (Malec 1999). However, several methodological limitations have been pointed out (Malec 1999, Cytrynbaum et al. 1979, Hurn et al. 2006) and the debate on its merits and demerits continues to date (Ertzgaard et al. 2011, Tennant 2007, Turner-Stokes 2009, Turner-Stokes et al. 2009). These will be discussed in detail in section 5.4.3.1.

In the mid 1980s, the concept of goal setting from the field of Psychology was adapted and its application began to be explored in other settings, such as sports and exercise (Locke and Latham 1985). Since then, it has continued to be used in various sports and exercise settings (Annesi 2002, Mellalieu et al. 2006, Wanlin et al. 1997), with publications of reviews in this field, providing evidence of its usefulness (Kyllo and Landers 1995, Weinberg 1994). During this time goal setting was not only used to increase task performance, but also to improve adherence to exercise (Annesi 2002).

The earliest reference where the terms ‘goal’ and ‘patient’ appear together dates back to 1974 (Becker et al. 1974). In this paper, the authors discuss a goal sheet that helped professionals in discussing treatment priorities with their patients and the usefulness of the tool (Becker et al. 1974). However, exploration of goal setting in rehabilitation began only in the mid 1980s (Chiou and Burnett 1985) and started to gain momentum in

the 1990s and the early 2000s (Wade 1998, Davis et al. 1992, Holliday et al. 2005, Playford et al. 2000). The past seven to eight years (i.e. 2003 to 2010) have seen a dramatically increased interest in this field, with the publication of several papers (Levack et al. 2006a, Levack et al. 2006b, Playford et al. 2009, Scobbie et al. 2009). In 2009, an entire journal issue was dedicated to goal setting by 'Clinical Rehabilitation' (Wade 2009). This growing interest in goal setting led to the investigation of goal setting in the field of exercise after stroke, discussed next in more detail.

2.7.3. **Goal setting for exercise after stroke**

Goal setting for exercise after stroke appears to be a relatively new field. A basic search in the 'Pubmed' database with the keywords 'goal setting', 'exercise OR physical activity', and 'stroke OR brain injury' revealed only four relevant articles (Reed et al. 2010, Harrington et al. 2010, Huijbregts et al. 2009, Huijbregts et al. 2008). Interestingly, these studies were fairly recent, demonstrating the developing interest in this area.

One study (n=30) used a prospective longitudinal cohort design to evaluate a new self-management programme called Moving On after Stroke (MOST) (Huijbregts et al. 2008). The MOST programme was designed specifically for stroke survivors, incorporating elements of both education and exercise, with the aim of improving self-efficacy and promoting self-management. This programme was delivered as a two hour session, of which one hour was an education session including goal setting and problem solving, and the second hour was devoted to exercise. The MOST programme was compared with another education-only programme which had no element of goal setting. GAS was used to set both short-term and long-term goals in this programme. Assessments were conducted pre- and post intervention and 12 weeks post intervention. Between group changes were not significant, however, the authors reported that the scores for the Activity-specific Balance Confidence Scale (a measure assessing balance

confidence) was approaching significance in favour of the MOST programme. Of the 18 participants in the MOST group, 13 achieved or exceeded their long-term goals. The authors also collected data on whether the participants were participating in any other formal exercise program outwith the study and the results indicated that the participants in the MOST group were more likely to participate in exercise classes than the other group. Although the authors controlled for the high exercise participation evident in the MOST group at baseline, this result may be confounded because the participants chose which group they wanted to join in at the start, and there was no randomisation. This would mean that participants preferring exercise would have chosen the MOST programme, and their desire to exercise may have led to the uptake of more exercise, and hence this change may not be attributed to the MOST programme alone. Despite the limitations, this study demonstrated that goal setting is feasible in this population. However, all the goals set were not specifically related to exercise, and the intervention contained various elements of education and therefore the unique contribution of goal setting (if any) could not be determined.

The second study identified evaluated the feasibility of the telehealth delivery of the MOST programme discussed above (Huijbregts et al. 2009). As the aim of the study related to the telehealth delivery, less information was provided on goal setting. Further, the limitations identified for the above study with respect to the effectiveness of goal setting per se. were applicable to this study as well.

The third and fourth articles identified were evaluations of a community based exercise and education scheme for stroke survivors, of which goal setting was a part (Reed et al. 2010, Harrington et al. 2010). The effectiveness of the intervention was evaluated through a high quality RCT (n=243), comparing the intervention with usual care (no exercise and education, only information provision) (Harrington et al. 2010). Significant changes were demonstrated in favour of the experimental intervention in outcome measures of social and physical integration and quality of life at the end of the

intervention, follow-up assessments at six months and one year post intervention. Although the authors mentioned that the key role of the volunteers coordinating the education session was to help stroke survivors in setting goals, very little information on goal setting was provided. It is not clear if the goals set were related to exercise and if the exercise programme was tailored to help in goal achievement. Moreover, no outcome measures to determine goal achievement were used. The corresponding qualitative study exploring the participants' experiences of the exercise and education programme identified that the participants positively valued the exercise and goal setting component of the intervention (Reed et al. 2010). However, no more details on goal setting were provided. Despite the lack of information, these studies have demonstrated that goal setting is feasible in the exercise after stroke setting.

2.7.3.1. Gaps in the literature

Based on the above literature review, it is evident that there is a lack of information on the effectiveness and experiences of goal setting in exercise after stroke. Due to the limited number of studies, there was a need to expand the literature search in order to understand the role and effectiveness of goal setting. Therefore, it was decided to explore goal setting in rehabilitation in general, with more focus on stroke rehabilitation, and this is discussed next.

2.7.4. Goal setting in rehabilitation

In rehabilitation, goal setting is used for a number of reasons, such as to improve patient outcome and task performance; to influence patient motivation and adherence; to improve patient self-efficacy, and satisfaction from rehabilitation; and finally, to monitor the effectiveness of the rehabilitation process (Levack et al. 2006b, Wade 2009, Wade 1999). In the sub-sections that follow, a brief overview of the effects, experiences, and methods of goal setting is presented.

2.7.4.1. Effects of goal setting

The possible benefits of goal setting in rehabilitation including stroke rehabilitation have been presented widely (Wade 1998, Levack et al. 2006a, Playford et al. 2009). At the time of designing the current programme of work (year 2009), most of the synthesised evidence in this area was comprised of either narrative reviews, or general discussions based on expert opinions and personal experiences (Wade 1998, Playford et al. 2009, Wade 2009, Armstrong 2008), with the exception of one systematic review by Levack et al. (2006a).

The systematic review by Levack et al. (2006a) included 19 RCTs, with a total of 852 participants. The investigations in the included studies were conducted in people with different health conditions, such as musculoskeletal disorders, disorders or injuries of the central nervous system, cardiovascular pathologies, endocrine/dietary disorders, and in populations of frail elderly (Levack et al. 2006a). Only four studies had included participants with stroke (Gauggel et al. 2001, Gauggel and Fischer 2001, Gauggel et al. 2002, Gauggel and Billino 2002). However, all four studies were by the same team, and had tested the effects of goal setting over only a short period of time, i.e. a few hours. Moreover, the tasks used in these studies were either simple arithmetic tasks (Gauggel et al. 2002, Gauggel and Billino 2002), reaction time tests (Gauggel et al. 2001), or the Purdue Pegboard Test (Gauggel and Fischer 2001), and therefore, not providing a true reflection of stroke rehabilitation with its predominantly complex interventions.

Although only RCTs were included in the above review, the authors were not able to quantitatively synthesise the evidence due to variability in the goal setting interventions. The methodological quality of the included studies was also low, with only five studies scoring six or more on the PEDro scale (of a maximum of ten). Therefore, the authors concluded, with caution, that there was mixed evidence for the effect of goal setting on programme outcomes, and limited evidence that it improves adherence to treatment

regimens in rehabilitation (Levack et al. 2006a). Nevertheless, the high number of studies reviewed suggests that goal setting is feasible in rehabilitation. However, it should be recognised that this review considered only one aspect of goal setting, i.e. its use to improve patient outcomes as determined by standardised outcome measures. It did not include studies that used goal setting for other reasons, such as to increase patient autonomy, to evaluate outcomes and to respond to contractual, legislative or professional requirements (Levack et al. 2006b). Therefore, some information on the overall effects of goal setting may not have been obtained.

In agreement with the findings of this review, other researchers also have agreed that goal setting may be effective, but that the evidence for its effectiveness is patchy (Wade 1998, Playford et al. 2009, Wade 2009, Armstrong 2008). However, all researchers in this area have advocated for collaborative goal setting, emphasising that goal setting is a core component of rehabilitation (Wade 1998, Davis et al. 1992, Playford et al. 2009, Wade 2009, Armstrong 2008, McClain 2005).

2.7.4.2. Experiences of goal setting

Recognition of the important role of goal setting in rehabilitation has been based not only on the effects of goal setting, but also on experiences of patients, carers and Health Care Professionals (HCPs) in relation to goal setting (Chen et al. 2002, Conneeley 2004, Holliday et al. 2007a, Kuipers et al. 2004, McGrath and Adams 1999, Nelson and Payton 1997, Payton et al. 1998, Young et al. 2008, Wressle et al. 1999a). As with the effects, experiences of goal setting have not been completely positive. Increased patient involvement in rehabilitation, and improved professional-therapist relationships have been seen as benefits of goal setting (Chen et al. 2002, Holliday et al. 2007a, Wressle et al. 1999a). On the other hand, issues such as patients' lack of insight, neurological impairments (e.g. cognitive problems), and professionals' lack of time have often been raised as difficulties in goal setting (Kuipers et al. 2004, Young et al. 2008, Wressle et

al. 1999a). However, most of these studies were with mixed population groups that included stroke patients, and therefore findings could not be generalised to stroke rehabilitation in particular. Nevertheless, these studies again demonstrated that goal setting is generally feasible in stroke rehabilitation.

2.7.4.3. Methods of goal setting

As mentioned earlier, variations in methods of goal setting may have contributed to problems in synthesising evidence on the effects and experiences of goal setting in rehabilitation. A fairly recent systematic review by Kamioka et al (2009) reviewed 165 reports to identify methods of goal setting in physical therapy, and its application to stroke. They identified eight different goal setting methods that are being used in physical therapy. These included: GAS, the Canadian Occupational Performance Measure (COPM), Treatment Evaluation by Le Roux's method, the Patient Goal Priority Questionnaire, the Patient Participation System, a 5-step process for writing functional goals, a goal forum intervention, and the goal-planning method at Rivermead Rehabilitation Centre (Kamioka et al. 2009). However, the authors concluded that more work on psychometric properties is required before any of these methods can be used in stroke rehabilitation (Kamioka et al. 2009). Variations in goal setting methods and minimal use of formal methods of goal setting have also been evident through surveys and consensus meetings (Holliday et al. 2005, Playford et al. 2009).

2.7.4.4. Gaps in the literature

The above exploration of goal setting in rehabilitation revealed gaps in the literature and also highlighted some important issues that need to be considered in relation to goal setting in stroke rehabilitation.

Firstly, due to the impact of stroke, the recovery process and prognosis, goal setting for people with stroke is likely to be different from other neurological conditions. The differences in goals between stroke and traumatic brain injury (TBI) patients were highlighted by Phipps and Richardson (2007). In their study, the stroke patients had more goals regarding home management and functional mobility, while the TBI patients had more goals related to leisure, community reintegration, vocational, and academic skills. The differences in age between the two groups (i.e. the stroke patients were on average 20 years older than the TBI patients) was cited as a reason for this difference in types of goals selected. Cognitive impairments that may feature in stroke patients and its impact on goal setting, both from the perspectives of patients and professionals, should also be considered. Further, it is believed that goal setting for a progressive neurological disorder such as multiple sclerosis would be different when compared with goal setting for stroke, i.e. goals may reflect maintenance or prevention of regression in progressive conditions, while goal setting in stroke may emphasise progression. In line with this argument, Van de Weyer et al. (2010) recognised that experiences of goal setting amongst professionals working with people with stroke may differ from those of professionals working with other neurological conditions. Therefore, it is essential that goal setting is considered specifically in relation to stroke rehabilitation.

Secondly, there is a need to conduct a systematic review to synthesise the current evidence of goal setting in stroke rehabilitation. The review by Levack et al. (2006a) did not specifically concentrate on stroke rehabilitation, and only included studies that used goal setting to improve patient outcomes and not for other reasons, as explored earlier (section 2.7.4.1). Moreover, the databases were searched only until June 2005 in that review, and it is expected that more studies will have been published since then, due to growing interest in the field. The more recent review of Kamioka et al. (2009) solely concentrated on the methods and not on effectiveness of goal setting. A number of other reviews have evaluated only the psychometric properties of certain goal setting tools, such as GAS and the COPM (Hurn et al. 2006, Donnelly and Carswell 2002). With

current interest in goal setting and with the growing number of studies, a systematic review to integrate all the evidence underpinning goal setting is required. In order to obtain a complete picture and understand the requirements for optimal clinical practice in goal setting, it is important not only to consider the effects of goal setting but also to synthesise experiences in relation to goal setting. Accordingly, a comprehensive systematic review on the effects and experiences of goal setting in stroke rehabilitation was undertaken as part of this current programme of work (study one). This systematic review is presented as chapter 4 of this thesis.

Thirdly, the lack of a single, standard method of goal setting for stroke rehabilitation is highlighted. The aforementioned systematic review planned as part of this programme of work is expected to provide more information on methods of goal setting in stroke rehabilitation.

Fourthly, it is necessary to identify and understand the theoretical perspectives underpinning goal setting in order to be able to explain the various reasons for implementing goal setting in rehabilitation, and the variation in the methods used for goal setting. This is discussed in the following section.

2.7.5. **Theoretical background of goal setting**

With goal setting having become an essential part of rehabilitation, it is crucial to analyse its theoretical foundations. Wade (2005, p.812) stressed that "a theory or explanatory model is essential to analyse any situation, to decide on actions and to define the actions and words used". Having a sound theoretical background to goal setting can help clinicians improve their understanding of the concept (what, why and how) and thereby their ability to explain it better to patients (Scobbie et al. 2009). Understanding how an intervention works in theory is also thought to help in the

development of new and effective techniques (Siegert and Taylor 2004). However, it has been recognised that the theoretical background in rehabilitation needs to be understood through theories from other disciplines such as social sciences, psychology and organisational settings (Playford et al. 2009, Scobbie et al. 2009, Siegert and Taylor 2004, Hart and Evans 2006, Siegert et al. 2004).

Researchers have advocated for several different theories in an attempt to explain goal setting in rehabilitation. A well-conducted systematic review identified five specific theories of behaviour change that were relevant to goal setting in rehabilitation (Scobbie, Wyke, & Dixon, 2009). The five theories were Bandura's Social Cognitive Theory, Locke and Latham's Goal Setting Theory, Schwarzer's Health Action Process Approach, Aspinwall and Taylor's Pro-active Coping Theory and Leventhal's Self Regulatory Model of Illness Behaviour. Based on the review of literature, the authors concluded that the first three theories in the above list were in a stronger position to explain goal setting in clinical practice than the rest (Scobbie et al. 2009). Siegert and Taylor (2004) proposed three theories, namely, Deci and Ryan's Self-Determination Model, Emmons's Subjective Goals and Well-Being, and Karniol and Ross's Temporal Influences on Goal Setting, to help with theory development of goal setting in rehabilitation. In another paper, the same group of authors used the Carver and Scheiers Control-Process model of Self-Regulation to explain goal setting (Siegert et al. 2004).

Although all the above suggested theories are different, some constructs are common and feature in most of the theories. These constructs include: self-efficacy, self-regulation, self-determination, motivation, feedback, personal experiences, coping planning, and the linking between distal (long-term) and proximal (short-term) goals. However, no one theory could provide complete explanations as to how goals can be or should be applied to clinical rehabilitation (Playford et al. 2009). This variation in the selection of theories demonstrates that the theoretical underpinning of goal setting in rehabilitation is not firm and still open to discussion and scrutiny.

Playford et al. (2009) put forth that it would be helpful to map the various theories of goal setting to identify areas that are relevant to rehabilitation. In line with this, Scobbie et al. (2009) argued that there was a need to develop and evaluate a goal setting conceptual and practice framework for use in clinical rehabilitation, a view also supported by Siegert and Taylor (2004). However, at the time of the design of this current programme of work, there was no such framework, and developing such a framework was not the focus of this work. Hence it was decided to choose one theory to be used in this work that was thought to best explain goal setting in rehabilitation.

Among the theories identified by researchers for goal setting, Bandura's Social Cognitive Theory (SCT) appeared to be stronger than the others for explaining goal setting for the following reasons. Firstly, most of the common constructs within theories such as self-efficacy, self-regulation, feedback, personal experiences, and linking between long-term and short-term goals were part of SCT, demonstrating the high relevance of the theory to goal setting. Secondly, this theory was the theoretical framework that was most used in the studies included in the systematic review by Scobbie et al. (2009) (13 studies of 24), highlighting its ability to explain goal setting. Thirdly, certain drawbacks were identified with the other theories. For example, although Locke and Latham's Goal Setting Theory has been evaluated in various fields such as work environments, sports and health (Locke and Latham 2002), its application to rehabilitation has been questioned (Playford et al. 2009). Questions were raised because the tasks involved in the studies implementing this theory in rehabilitation have been simple tasks such as mathematical addition, and were not true reflection of tasks used in rehabilitation (Gauggel and Fischer 2001, Gauggel and Billino 2002). On the other hand, SCT has been successfully applied to goal setting in rehabilitation, self-management and physical activity settings, as demonstrated in the systematic review of Scobbie et al. (2009). Fourthly, SCT was able to explain not only how goal setting would work, but also how this would lead to a behaviour change, which was in line with the focus of this programme of work (i.e. goal setting as a behaviour change

intervention). Therefore, the SCT was chosen as the theoretical framework for this programme of work. The theory and its evidence base are explained in more detail in the following sub-sections.

2.7.5.1. Bandura's Social Cognitive Theory (SCT)

Social Cognitive Theory looks at self-development, adaptation, and change in human behaviour (Bandura 2005). Bandura (2005, p.24) proposed that "people are self-organising, pro-active, self-regulating, and self-reflecting. They are contributors to their life circumstances not just products of them." He proposes that goals act as guides to motivate action (Bandura 2005). Self-efficacy and self-regulatory behaviour are the key elements of this theory (Bandura 2005)

Self-efficacy is defined as "people's judgement to organise and execute courses of action required to attain designated types of performances. It is not concerned with the skills one has but with judgements of what one can do with whatever skills one possesses" (Bandura 1986, p.391). Bandura also explains that there are two types of expectations associated with self-efficacy. Efficacy expectations are beliefs that are related to the ability to carry out a particular behaviour, whereas outcome expectations relate to a belief about whether the behaviour will produce a particular result (Bandura 1986). He emphasises that efficacy beliefs play a central role in the cognitive regulation of motivation (Bandura 1997). Efficacy beliefs contribute to motivation by influencing the type of challenges people undertake, the effort they put in the task, and the actions they take in the face of difficulties. Stronger perceived self-efficacy is associated with a higher level of motivation to set challenging personal goals, and a stronger commitment to the task to achieve the set goals (Bandura 1997).

Bandura (1986) identifies that self-efficacy beliefs need to be coupled with self-regulatory skills to achieve the best performance. As per Bandura (1997, p.51), self-

regulatory skills include “generic skills for diagnosing tasks demand, constructing and evaluating alternate courses of action, setting proximal goals to guide one’s efforts, and creating self-incentives to sustain engagement in taxing activities and to manage stress and debilitating intrusive thoughts”.

Self-efficacy beliefs and self-regulatory skills are thought to be influenced by enactive mastery experience and feedback. The enactive mastery experience enables individuals to overcome obstacles and work out a successful path that may help in future tasks (Bandura 1997). For individuals with lower self-efficacy beliefs, explicit and frequent feedback on progress can improve their efficacy beliefs and thereby improve their motivation (Bandura 1997).

Bandura also stresses the importance of forming sub-goals/proximal/short-term goals. He explains that self-motivation will be high and sustained, if long-term goals are combined with a series of attainable short-term goals that will guide the person’s efforts (Bandura 1997). Achieving sub-goals can provide the mastery skills that serve as an incentive to move towards the next target (Bandura 1997).

Further, it is suggested that personal goals regulate motivation and performance better than goals that are set for individuals by others (Bandura 1997, Schunk 1985). It is emphasised that when people own the goals, they tend to be more responsible in working towards the goals and self-evaluative. This self-evaluation is believed to help individuals in the development of skills especially those who have doubt about their capabilities (Bandura 1997, Schunk 1985, Lerner and Locke 1995). At the same time, it is identified that some individuals may need help in goal setting. This help should be provided in the form of advice on (i) how to set optimal goals, (ii) how to modify goals based on performance and attainment, and (iii) how to overcome barriers. Thereby, the help should be targeted to improve the individual’s skill of self-regulation and goal setting rather than setting the goals for them (Bandura 1997).

Finally, the SCT explains that goals explicitly act as guides and motivators for performance and implicitly build and strengthen efficacy beliefs. Goal attainment is believed to create self-satisfaction and thereby increase interest in what one is doing (Bandura 1997, Lerner and Locke 1995).

2.7.5.2. Evidence for the Social Cognitive Theory

As demonstrated by Scobbie et al. (2009), several studies have utilised the SCT to design and evaluate their intervention. In a study of 533 patients with Rheumatoid Arthritis, the researchers demonstrated that patients involved in a self-management programme based on SCT (of which goal setting was a part) significantly decreased their hospital visits over a two year period in spite of increasing disability (Lorig et al. 2001). The findings of this longitudinal study were strengthened by the large sample size, however, it should be noted that this was a longitudinal study with no control group. Similarly, the constructs within SCT have been used to predict physical activity behaviour and behaviour change. In a study of 153 community-dwelling older adults, self-efficacy was identified as the most important determinant of long-term physical activity as examined after six months and at 18 month follow-up (McAuley et al. 2003). Strong evidence is also available to support the notion that stronger self-efficacy beliefs are associated with higher chances of sustaining the effort needed to uptake and maintain a health-promoting behaviour (e.g. physical activity, healthy eating). In an integrative review of 23 studies, self-efficacy was identified as the strongest predictor of health-promoting lifestyles (Gillis 1993). Similarly, a meta-analysis of 56 articles published between 1981 and 1989 concluded that self-efficacy predicted subsequent health-related outcomes consistently (Holden 1991). Bandura has outlined around 50 studies in a wide range of disciplines as evidence for the positive role of self-efficacy in behaviour change, in a book entitled ‘Understanding and changing health behaviour’ (Bandura 2000).

2.7.5.3. Section summary

In summary, the SCT has facilitated understanding of the role of goal setting in promoting a behaviour change. It could be said that goal setting and goal attainment could improve one's self-efficacy through mastery experience and feedback of performance. The increased self-efficacy in turn could help an individual to set more goals and attain them. This increased confidence and motivation could then help the individual improve and/or sustain the behaviour of focus. Exploration of this theory has also led to understanding of the key elements required within a goal setting intervention for it to be able to promote behaviour change. Accordingly, these were taken into consideration for the goal setting intervention used in this programme of work (see chapter 5 for details).

Having established the theoretical framework to be used for this work, it is essential to consider current policies and guidelines to ensure that the programme of work is in line with current recommendations.

2.7.6. **Current policies and guidelines**

Goal setting is recommended as part of rehabilitation for several patient populations in various clinical guidelines and best practice guidelines across several countries, such as the UK (SIGN 2010, Intercollegiate Stroke Working Party 2008), Australia (National Stroke Foundation 2010, Goble and Orcester 1999), Canada (Lindsay et al. 2010) and New Zealand (Ministry of Health 2004). In the UK, the National Clinical Guidelines for Stroke have a separate section recommending goal setting as part of stroke rehabilitation, based on evidence and consensus (Intercollegiate Stroke Working Party 2008). They recommend that goal setting should be a part of usual stroke rehabilitation with all patients participating in the process of goal setting. The features of an ideal goal are also outlined (Intercollegiate Stroke Working Party 2008). These recommendations

are presented in Table 2.3. These guidelines have since been updated; however, the recommendations regarding goal setting remain the same (Intercollegiate Stroke Working Party 2012).

Table 2.3: Recommendations for goal setting in the National Clinical Guidelines for Stroke

(Intercollegiate Stroke Working Party 2008, p.37)

"Every patient involved in the rehabilitation process should: - have their wishes and expectations established and acknowledged; - participate in the process of setting goals unless they choose not to or are unable to participate because of the severity of their cognitive and linguistic impairments; - be given help to understand the nature and process of goal setting, and be given help (e.g. using established tools) to define and articulate their personal goals."
"The rehabilitation process should have goals that: - are meaningful and relevant to the patient; - are challenging but achievable; - include both short-term (days/weeks) and long-term (weeks/months) targets; - include both single clinicians and also the whole team; - are documented, with specified, time-bound measurable outcomes; - have achievement evaluated using goal attainment; - include family members where appropriate; and are used to guide and inform therapy and treatment."

The emphasis on goal setting placed in the current guidelines further validates the interest and the need to explore goal setting for exercise after stroke.

2.8. Goal setting for exercise after stroke as a complex intervention

The Medical Research Council (MRC) put forth a framework for the design and evaluation of complex interventions in the year 2000, and updated it in the year 2008 (Craig et al. 2008, Campbell et al. 2000). As per the framework, complex interventions are described as, "interventions that contain several interacting components, but they have other characteristics that evaluators should take into account" (Craig et al. 2008 p.979). Some of the characteristics of complex interventions include: high number of interacting components within the experimental and control interventions, high numbers and/or difficulty of behaviours required by those delivering or receiving the intervention, high numbers and/or variability of outcomes, and greater degree of flexibility or tailoring of the intervention required.

Person-centred goal setting could be classed as a complex intervention due to the greater degree of flexibility required for the intervention to be individualised, and also due to various mechanisms through which goal setting is expected to work. Stroke by itself is a complex disease with varying degrees of severity and recovery levels. Exercise after stroke has also been considered a complex intervention. Therefore, person-centred goal setting for exercise after stroke needs to be considered a complex intervention.

To design and evaluate a complex intervention, the MRC framework recommends some key elements which are presented in Table 2.4.

Table 2.4: Key elements for developing and evaluating a complex intervention

(Craig et al. 2008)

Key elements	Development method
Development: Adopt a systematic approach in the development of the intervention.	• Use best available evidence. • Use appropriate theory. • Modelling process and outcomes
Feasibility and piloting: Implement a carefully phased approach to test the intervention.	• Conduct several pilot studies to identify and modify uncertainties in the design and content of the intervention. • Conduct pilot studies to assess the feasibility issues. • Conduct an exploratory trial with the finalised intervention to identify sample size.
Evaluation: Evaluate the intervention.	• Conduct a definite trial.
Implementation: Implement the intervention.	• Disseminate the results widely. • Monitor the implementation. • Conduct follow-up and further research.

These key elements were planned to be followed in the design and evaluation of the person-centred goal setting intervention for exercise after stroke in this programme of work. The design of all the studies conducted as part of this work followed the MRC framework recommendations, which is referred to where appropriate throughout this thesis. However, it should be noted that as this programme of work was conducted as part of a PhD degree qualification, with time and resource restrictions, it was not possible to complete all the key stages outlined in the above table (Table 2.4). The stages

followed and the justification for each of these is presented later in this chapter (section 2.10).

In order to evaluate a complex intervention, it is essential to consider and select appropriate outcome measures as discussed next.

2.9. **Selection of outcome measures**

The underlying belief for this programme of work was that person-centred goal setting within exercise after stroke may contribute to uptake and/or maintenance of physical activity in the long-term. Therefore, outcome measures that would reflect the target behaviours (i.e. goal attainment and physical activity) were considered, and six outcome measures were selected (Figure 2.1). Of these, the Canadian Occupational Performance Measure (COPM) could be used both as a tool for goal setting and as an outcome measure for goal attainment, and hence is discussed later in chapter 5, section 5.4.3.2, as part of the development of a goal setting intervention. The other five outcome measures are discussed in detail in the following sub-sections, along with the justification for its selection and its psychometric properties.

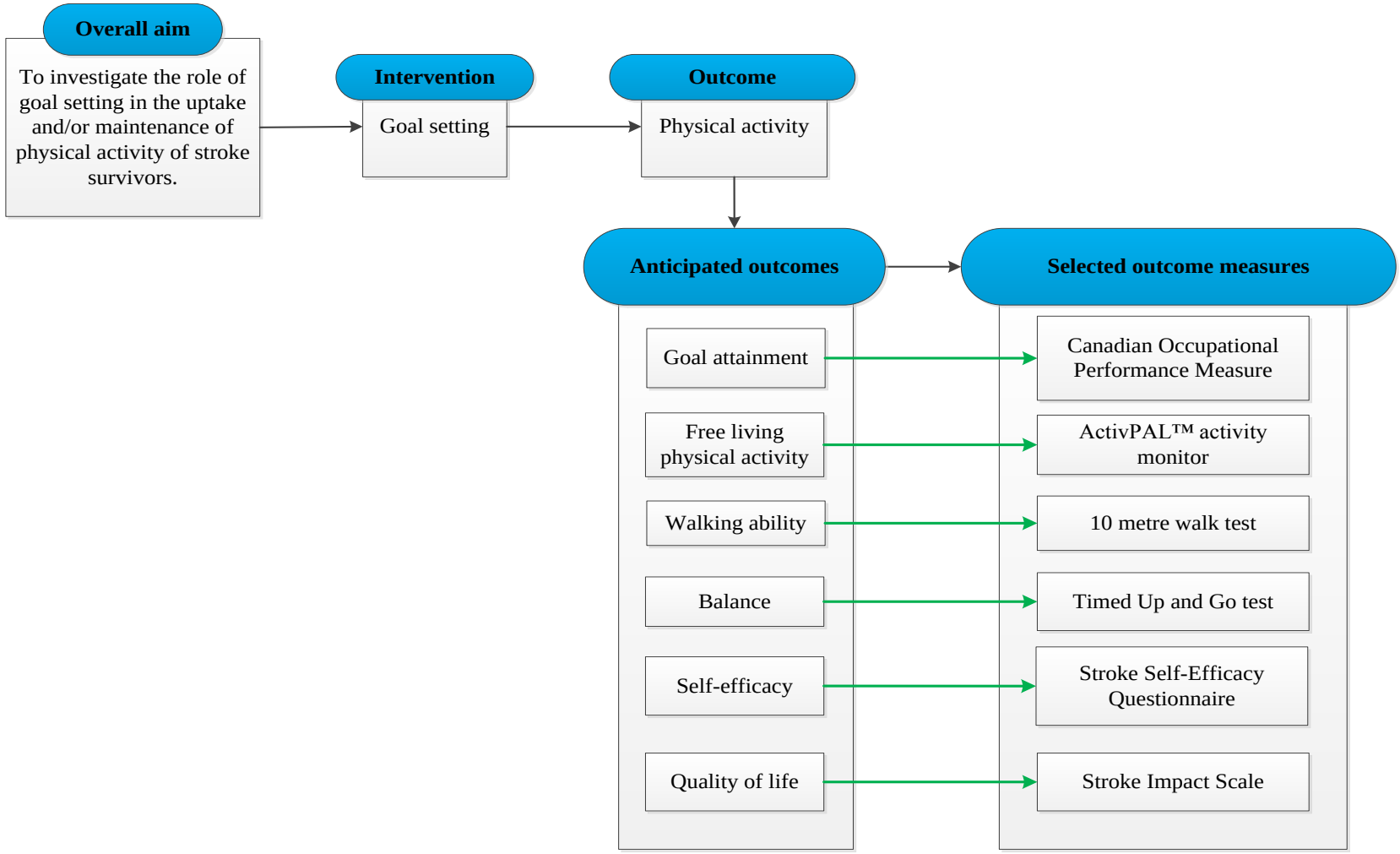

Figure 2.1: Rationale for the selection of the outcome measures

2.9.1. **Measurement of free-living physical activity - activPAL™ activity monitor**

As mentioned above, the target behaviour of this programme of work was physical activity and hence, measurement of physical activity was considered the primary outcome of interest. Physical activity measurement can help to track adherence to physical activity recommendations and to identify physical inactivity (Berlin et al. 2006, Gebruers et al. 2010). However, it has been recognised that measurement of physical activity behaviour is difficult due to its complexity, and that the availability of a number of measurement techniques presented difficulty in the selection of an appropriate tool (Hagströmer et al. 2007, Dale et al. 2002). Both subjective and objective methods are available to measure physical activity (Dale et al. 2002). However, subjective methods such as questionnaires and diaries rely on self-report, recall and honesty of the participant and hence their validity and reliability have been questioned (Hagströmer et al. 2007, Dale et al. 2002, Sallis and Saelens 2000). Moreover, researchers have documented that these subjective methods tend to overestimate physical activity performance (Dale et al. 2002, Sallis and Saelens 2000). Therefore, objective methods of measuring physical activity have been recommended.

Although precise, objective methods such as indirect calorimetry and doubly labelled water, are invasive, expensive and do not assess patterns of physical activity; therefore they may not be suitable for measuring free-living physical activity (Dale et al. 2002). Pedometers and accelerometers are objective measurement methods suited to this purpose (Berlin et al. 2006, Dale et al. 2002). However, pedometers are reported to have a higher number of disadvantages over accelerometers, such as their ability to measure only step count and not patterns of activity (Berlin et al. 2006, Dale et al. 2002) and a reduction in accuracy of measurement with high and low speeds (Bassett Jr. et al. 1996, Cyarto et al. 2004).

Accelerometers, on the other hand, are able to measure a range of physical activity variables, such as duration, frequency, number of transitions, and number of steps, and some are able to classify patterns of activity based on change in posture (Gebruers et al. 2010, Hagströmer et al. 2007, Dale et al. 2002, Ward et al. 2005). Due to the numerous benefits, use of accelerometers is on the increase and several models are available, each with their own advantages and disadvantages (Berlin et al. 2006, Gebruers et al. 2010, Ward et al. 2005). The best practice recommendations put forth by Ward et al. (2005) emphasise that product reliability, availability of technical support, practicality, and cost must be considered when monitors are selected for use. They further suggest that the selected instrument should have sufficient data processing and storage capacity for measurement over a longer duration, and should be portable and easy to use (Ward et al. 2005). Based on these recommendations, the activPAL™ manufactured by PAL Technologies Ltd, Glasgow, UK, was selected for use in this programme of work.

The activPAL^{TM} is a small (53mm x 35mm x 7mm), lightweight (15g) activity monitor worn on the anterior aspect of the thigh (PAL Technologies Ltd 2010) (Figure 2.2). The device contains a sensing element, a microprocessor and a recording element. The sensing element of the activPAL™ used in this study is a uni-axial accelerometer which responds to gravitational acceleration as well as the acceleration resulting from segmental movement. The microprocessor controls the processing and recording of the sensor signal and the communication with a host personal computer (PC). Data are recorded at 10 Hz for each 15 second time interval (epoch). The activity classification profile is created using the "Intelligent Activity Classification" (PAL Technologies Ltd 2010). The activPAL™ interfaces via a docking station and USB connection with a Windows compatible PC (Figure 2.2). Using proprietary algorithms, the activity pattern can be analysed. The software allows data to be presented in various ways (weekly view or day view, graphically or quantitatively), according to the needs of the user (PAL Technologies Ltd 2010). The activPAL™ has a four megabyte memory capacity and this allows it to record for periods in excess of seven days (PAL Technologies Ltd

2010). The variables obtained from the activPAL™ include: time spent in sitting/lying, standing, stepping, number of steps, number of sit-to-stand transitions, and number of stand-to-sit transitions.

Figure 2.2: Image of an activPAL™ activity monitor placed on a docking station (Source: PAL Technologies Ltd, 2010)

The validity and the reliability of the monitor has been evaluated both in healthy populations over a wide range of ages (Grant et al. 2008, Grant et al. 2006, Ryan et al. 2006, Dowd et al. 2012, Aminian and Hinckson 2012) and in some impaired populations, such as patients with low-back pain (Ryan et al. 2008), older people with impaired function (Taraldsen et al. 2011), and chronic obstructive pulmonary disease (Ng et al. 2012). Various variables measured by the activPAL™ have been evaluated such as step counts (Grant et al. 2008, Baer and O'Loughlin 2007), number of transitions (Harris et al. 2006) and time spent in different postures/activities (Grant et al. 2006, Ryan et al. 2006, Ryan et al. 2008). In most studies, the activPAL™ was evaluated against video observation, which was deemed the criterion measure (Grant et al. 2008, Grant et al. 2006, Ryan et al. 2006, Taraldsen et al. 2011). One study selected a discrete accelerometer-based activity monitor as the criterion measure (Godfrey et al. 2007), while one study used direct observation (Harris et al. 2006). The activPAL™ was also

compared to several pedometers, and other types of accelerometers, and the results showed that the activPAL™ performed better (Grant et al. 2008, Ryan et al. 2006, Baer and O'Loughlin 2007).

Of studies evaluating the psychometric properties of the activPAL™ monitor, only two included participants with stroke (14 participants) (Taraldsen et al. 2011, Harris et al. 2006). However, the study of Taraldsen et al. had a mixed population (participants with impaired function and hip fracture and n=14 stroke participants), thereby limiting its transferability to the stroke population. The study of Harris et al. (2006) (n=6) evaluated only the validity of the monitor for the measurement of the number of transitions, and none of the other measurement variables. A further search of the Pubmed database (keywords activPAL AND stroke) revealed no other publication to demonstrate the psychometrics properties of activPAL™ monitor in the stroke population. Interestingly, despite this the monitor has been used as an outcome measure in studies with stroke survivors (Touillet et al. 2010, Kottink et al. 2007, Britton et al. 2008, Bartolo and Egerton 2005). The validation studies conducted in older adults have been used as justification in some of these studies, excluding the study of Britton et al. (2008). However, parameters such as gait pattern (i.e. reduced heel strike and/or toe-off) and speed of walking (slow walking speeds) may differ between a healthy older adult and a stroke survivor. These parameters are likely to affect the acceleration signal, and therefore, extrapolating results from one population to another may not be valid. Therefore, based on the above review of the literature relating to the activPAL™, a need to evaluate its validity and reliability for use with people who have had a stroke was identified and this was incorporated as one of the aims of this programme of work. The aims are presented in more detail as chapter 3.

2.9.2. **Ten metre walk test**

As mentioned earlier the target behaviour for this programme of work was physical activity, and walking ability was considered one of the main components that would influence physical activity (Brazzelli et al. 2011). Hence, the need to measure gait performance was recognised. Walk tests have been recommended for this, of which, the ten metre walk test (10MWT) was chosen as one of the outcome measures for this work.

The 10MWT was first proposed for use in stroke survivors by Wade et al. (1987). Walking a distance of ten metres has been recognised as one of the mobility milestones in stroke recovery, and hence considered meaningful both in clinical and research settings (Smith and Baer 1999, Watson 2002). The 10MWT has been evaluated widely for its psychometric properties in stroke rehabilitation. The validity of the test was established, with the test demonstrating adequate to excellent correlations with other measures, such as the Barthel Index (r = 0.78), the Berg Balance Scale (r = 0.627), the Dynamic Gait Index (r = 0.87), the Functional Gait Assessment (r = 0.85), the Functional Reach Test (r = 0.349), the Six Minute Walk Test (r = 0.89), and the Timed Up and Go (TUG) test (r = 0.84) (Flansbjer et al. 2005, Tyson and Connell 2009, Lin et al. 2010a, Wolf et al. 1999). Similarly, the test showed excellent intra-rater (ICC =0.87 to 0.88), inter-rater (ICC = 0.998) and test-retest reliability (ICC = 0.95 to 0.99) (Wolf et al. 1999, Collen et al. 1990). The 10MWT was also sensitive and responsive to change (Perera et al. 2006). The simplicity of the tool, along with its psychometric properties prompted Wade to describe the 10MWT as an “almost perfect measure” (1992, p.78). Moreover, it was believed that the wide use of this test, as evident in the review of Brazzelli et al. (2011), would allow for meaningful comparison of findings in the latter stages of this work. These properties justify the choice of the measure for this work.

The protocol proposed by Watson (2002) was followed for this test in this programme of work. This protocol was chosen as it was proposed for use with neurologically affected populations (Watson 2002).

2.9.3. **Timed Up and Go test**

Balance was considered to be another important measure that would have an impact on physical activity, and hence was selected as one of the outcomes to be included for this programme of work. The TUG test was chosen as an appropriate measure for this work.

The TUG test was developed as a variation of the 'Get Up and Go test', the difference being in the scoring system (Mathias et al. 1986, Podsiadlo and Richardson 1991). Performance on the original test was scored by an observer on a scale of 1 to 5 (Mathias et al. 1986). However, this scoring system had poor inter-rater reliability and hence the new method of scoring the test on the time taken to complete the task was introduced (Podsiadlo and Richardson 1991). This modified test was called the TUG test.

In the TUG test, on the command "go", the participants are asked to stand up from a chair, walk a distance of three meters, turn around, walk back to the chair and sit down. Timing begins at the instruction "go" and stops when the participant is seated.

The TUG test is easy to administer and takes only a few minutes to complete (Finch et al. 2002). Although the TUG test is one of the commonly used measures in stroke research, there is a dearth of literature on its psychometric properties in this population (Ng and Hui-Chan 2005, Flansbjer et al. 2005). However, the test was designed for the frail elderly population and there are several publications in this population on its psychometric properties (Podsiadlo and Richardson 1991, Steffen et al. 2002, Brooks et al. 2006, Berg et al. 1992). The validity of the test has been demonstrated on comparison with other tests, such as the Barthel Index (r = -0.78), Berg Balance Scale (r = -0.81),

Functional Independence Measure (r = -0.59), Sickness Impact Profile (r = 0.40), gait speed (*r* = -0.61), and gait velocity (r = 0.99), with most of the study results showing evidence of moderate to excellent correlations with the TUG test (Ng and Hui-Chan 2005, Flansbjer et al. 2005, Brooks et al. 2006, Berg et al. 1992). Similarly, all aspects of reliability (inter-rater (ICC = 0.99), intra-rater (ICC = 0.92), and test-retest (ICC = 0.96)) have been rigorously tested, with results demonstrating adequate to excellent reliability for the use of the TUG (Podsiadlo and Richardson 1991, Steffen et al. 2002). Since stroke is common in the frail elderly, these results can cautiously be extrapolated to the stroke population. As with the case of the 10MWT, it was believed the wide use of the TUG test would enable comparison with other published literature in the latter stages of this work, thereby justifying the choice of the tool for this study.

2.9.4. **Stroke Self-Efficacy Questionnaire**

Self-efficacy is one of the major constructs of the chosen theory underpinning the person-centred goal setting intervention (Bandura's Social Cognitive Theory (SCT)). Hence, it was considered essential to measure the individual's self-efficacy. For this purpose, the Stroke Self-efficacy Questionnaire (SSEQ) was chosen. A copy of this measure is attached as Appendix 1.

The SSEQ was developed between 2004 and 2006 and after several pilot tests, it was published in 2008 (Jones et al. 2008). The questionnaire was designed using the principles of the SCT for use by practitioners to measure patients' judgements of self-efficacy in specific domains of functioning relevant to individuals following stroke (Jones et al. 2008).

The SSEQ has 13 questions; some concentrate on functional activities such as going to bed and walking, while the other questions relate to psychological factors such as coping with frustration. For each of the 13 questions, the participant is asked to rate his/her

current confidence in relation to completing that task on a scale of 0 to 10, where '0' is not at all confident and '10' is very confident.

As part of tool development, the validity of the measure was established through discussion with experts, and comparison with the Falls Efficacy Scale (Jones et al. 2008). Although the developers state in the same paper that other measurement properties such as reliability and sensitivity have been demonstrated, no actual data or publication could be found to confirm this (Jones et al. 2008). Since the publication of the tool, it has been used in some studies, however, it should be recognised that in most of these studies the developers were involved (Jones et al. 2009, McKenna et al. 2011, Sampson and Mercer 2011). Despite these limitations, this is the only tool that has been developed specifically for stroke survivors to measure self-efficacy. Moreover, its link with the SCT adds to its strength and therefore, the choice of the tool for this study could be justified.

2.9.5. **Stroke Impact Scale**

The impacts of stroke on day-to-day life and overall health status were expected to be reflected in the goals the participants set, and might also affect their performance in achieving the goals set. Therefore, it was considered important to have a measure to capture quality of life, and the Stroke Impact Scale (SIS) version 3.0 was chosen for this purpose. A copy of this measure is attached as Appendix 2.

The Stroke Impact Scale (SIS) is a stroke-specific, self-report, health status measure. The SIS was developed at the Landon Center on Aging, University of Kansas Medical Center, and first published as version 2.0 (Duncan et al. 1999). This version was comprised of 64 items in eight domains. The measure went under review and, based on the Rasch analysis process results, five items were removed from the scale, and the current version 3.0 was created (Duncan et al. 2001). The SIS version 3.0 includes 59

items and assesses eight domains: strength (four items), hand function (five items), ADL/Instrumental ADL (IADL) (10 items), mobility (nine items), communication (seven items), emotion (nine items), memory and thinking (seven items), and participation/role function (eight items). At the end of the scale there is a visual analog scale item on stroke recovery where the participant is asked to rate his/her recovery from stroke on a scale of 0 – 100. All the other items are rated on a five-point Likert scale in terms of the difficulty the participant has experienced in completing them during the past week. Aggregate scores, ranging from 0 to 100, are then generated for each domain. The four physical domains (strength, hand function, mobility, and ADL/IADL) can be summed to create a single, physical dimension score.

The SIS was highlighted as a promising measure in the category of patient-reported outcome measure specific to stroke (Jenkinson et al. 2009) and was considered to provide the most comprehensive evaluation of various aspects of life function relating to health after stroke (Salter et al. 2008). The validity of the scale has been demonstrated by the adequate to excellent correlations with other measures, such as the Barthel Index ($r = 0.52$ to 0.80), SF-36 ($r = 0.45$ to 0.84), WHO Quality of Life Brief Scale ($r = 0.40$ to $r = 0.63$) and the Zung Depression Score ($r = -0.62$) (Duncan et al. 1999, Duncan et al. 2002, Lin et al. 2010b, Edwards and O'Connell 2003). Other psychometric properties, such as reliability (inter-rater: $r = 0.43$ to 0.82, test-retest: $r = 0.70$ to 0.92), responsiveness, and sensitivity, have also been well established for the SIS (Duncan et al. 1999, Lin et al. 2010b, Duncan et al. 2003). Another strength of this measure was that stroke survivors were involved in the development of the tool (Duncan et al. 2001). Thus, the choice of this stroke-specific quality of life measure for the study could be justified.

2.9.6. **Section summary**

Five outcome measures were selected for use in this programme of work. Exploration of the psychometric properties of these measures revealed that the accuracy of the activPAL™ activity monitor needs to be established in a stroke population.

2.10. **Gaps in the literature**

The focus of this programme of work was on goal setting as a behaviour change intervention for exercise after stroke. On exploring the literature, the following gaps were identified:

(i) The specific role of person-centred goal setting in exercise after stroke has not been researched, to our knowledge.

(ii) The evidence for the effectiveness of goal setting in stroke rehabilitation has not been synthesised, to our knowledge. In addition, the experiences of goal setting of both people who have had a stroke and of health professionals involved in their care has also not been evaluated.

(iii) There is an apparent lack of a formal method of goal setting that could be used for exercise after stroke setting. However, no firm conclusions could be reached regarding this due to the lack of the evidence for the effectiveness of goal setting in stroke rehabilitation, as stated above.

(iv) The validity and reliability of the activPAL™ activity monitor has not been evaluated in a stroke population.

In order to address these gaps in the literature, five interlinked studies were conducted. As stated in section 2.8, the MRC framework for complex interventions was followed to design these studies. The rationale for each study and its aims is presented in more detail in the next chapter (chapter 3).

2.11. **Chapter summary**

The aim of this chapter was to introduce the background and rationale for this programme of work. Accordingly, stroke was introduced as a disabling condition that leads to low levels of physical fitness. The importance and benefits of physical fitness training or exercise training were emphasised. However, it was identified that long-term maintenance of gained benefits was low, and that several barriers existed for the uptake and/or maintenance of exercise after stroke. Goal setting as a behavioural change intervention was considered in detail and several gaps in the literature were identified. Goal setting was also identified as a complex intervention, and therefore it was decided to follow the MRC framework for developing and evaluating complex interventions to evaluate goal setting for exercise after stroke. The overall aims of this programme of work and the aims of the individual studies are presented in the next chapter (chapter 3).

3. **AIMS**

3.1. **Introduction**

In this chapter, the overall aims of this programme of work are presented, followed by the rationale for the individual studies and the aims for each of these studies. Since the studies were interlinked, findings from one study determined the specific aims and design of the next study. Therefore, more specific research questions for each of the studies are provided in the individual chapters, as findings emerged.

3.2. **Overall aims**

As highlighted in the previous chapter, the focus of this programme of work was on goal setting for exercise after stroke. The overall aim of this work was to investigate the role of goal setting in the uptake and/or maintenance of physical activity of stroke survivors, by designing and evaluating an evidence-based, theoretically-driven goal setting intervention in an exercise after stroke setting. The primary research question was:

(i) What is the role of goal setting in the uptake or maintenance of physical activity of stroke survivors involved in an exercise after stroke setting?

It was hypothesised that person-centred goal setting and goal attainment through principles of self-efficacy and self-regulation would help stroke survivors to uptake and/or maintain physical activity in the long-term. In order to address the above research question, five interlinked studies were designed in line with the MRC framework for developing and evaluating complex interventions (Figure 3.1). The rationale and the aims of each of these studies are presented in the following sections.

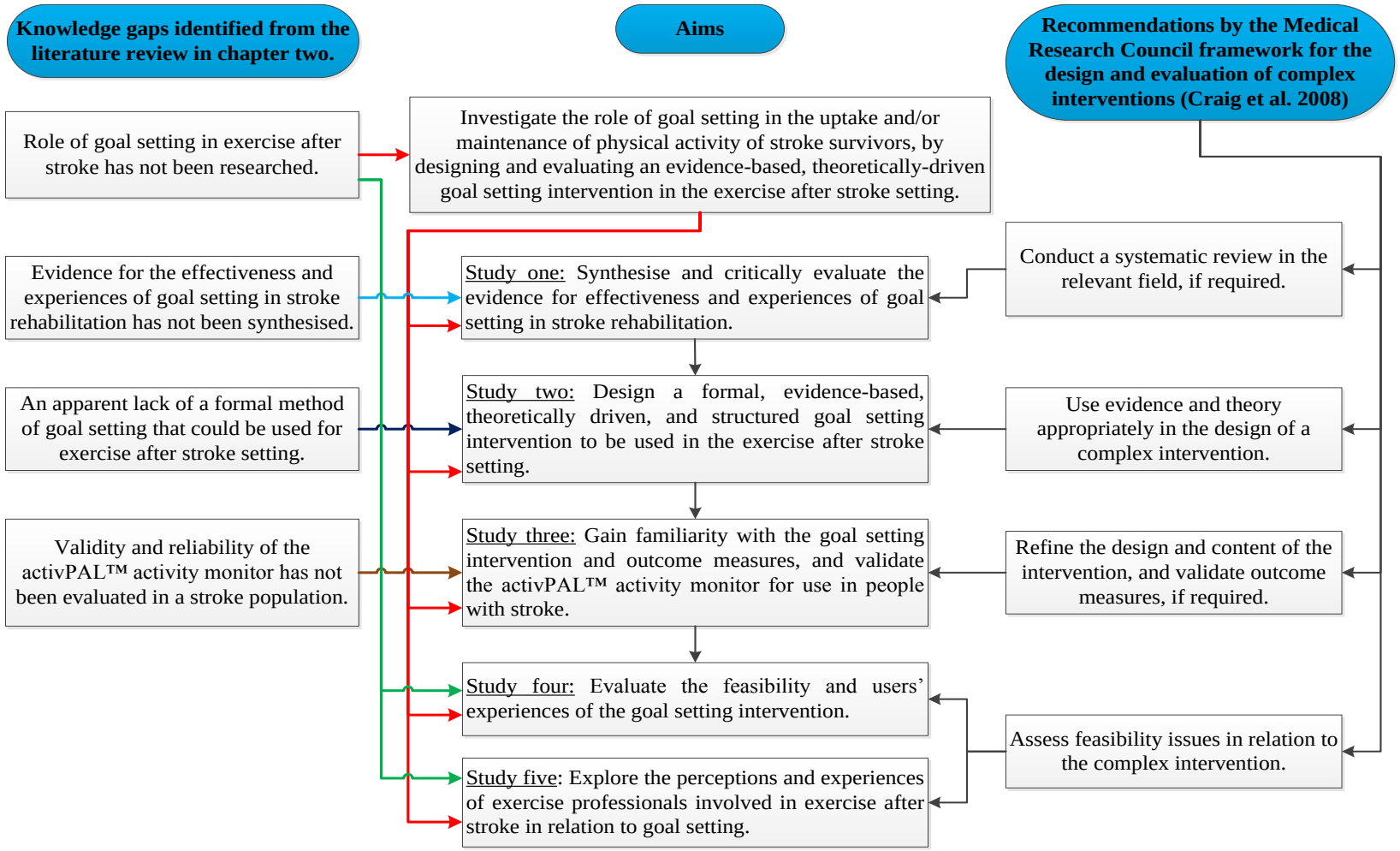

Figure 3.1: Knowledge gaps and overview of aims in line with the MRC framework for complex interventions

3.3. **Study one**

As per the aforementioned MRC framework, the first step in the design of a complex intervention is to use the available evidence and theory effectively. A thorough analysis of the existing theories on goal setting in section 2.7.5 revealed that there was no need to develop a new theory of goal setting. Of the existing theories, the SCT was chosen to underpin the goal setting intervention employed in this programme of work. The Council also recommends that a systematic review should be undertaken in the relevant field if there are no recent high quality systematic reviews (Craig et al. 2008). As discussed earlier in section 2.7.4.4, exploration of the literature on goal setting in stroke identified the need for a systematic review.

Therefore, a systematic review was conducted as the first study for this programme of work, with the following aims:

(i) To evaluate, critically appraise and synthesise the evidence for the effectiveness of goal setting in stroke rehabilitation.
(ii) To evaluate, critically appraise and synthesise the evidence for the experiences of goal setting in stroke rehabilitation.

This systematic review is presented as chapter 4 of this thesis.

3.4. **Study two**

In line with the modelling phase of the MRC framework, the next step was to design or modify a goal setting intervention to be used in exercise after stroke, based on the evidence gathered from study one. This intervention development was undertaken as the second study of this programme of work, with the following aim:

(i) To design a formal, evidence-based, theoretically driven, and structured goal setting intervention to be used in the exercise after stroke setting.

This intervention development study is presented as chapter 5 of this thesis.

3.5. **Study three**

The next stage in MRC framework was to refine the design and content of the intervention. Within this piloting phase, it is recommended that appropriate outcome measures are selected to evaluate the intervention under study, and validate these measures, if required. A review of literature relating to the selected outcome measures revealed that the activPAL™ activity monitor required validation for use in the stroke population (refer to section 2.9.1) Therefore, a pilot study was conducted as the third study of this programme of work, with the following aims:

(i) To pilot-test the goal setting intervention developed in the previous study (study two).
(ii) To gain familiarity with the application of the other selected outcome measures (i.e. 10MWT, TUG test, SIS, SSEQ, COPM).
(iii) To evaluate the validity and reliability of the activPAL™ activity monitor for use in people with stroke.

This pilot study is presented as chapter 6 of this thesis.

3.6. **Study four**

Assessing the feasibility of the person-centred goal setting intervention within an exercise after stroke setting was the next step as per the MRC framework. Accordingly, a mixed methods study was undertaken as study four of this programme of work, with the following aims:

(i) To examine the feasibility of the goal setting intervention developed in studies two and three for exercise after stroke.
(ii) To explore the participants' experiences of the goal setting intervention.
(iii) To analyse the changes observed in the selected outcome measures over the study duration.

This mixed methods study is presented as chapter 7 of this thesis.

3.7. **Study five**

As part of assessing the feasibility of the goal setting intervention in line with the MRC framework, it was essential to explore the experiences of exercise professionals who would be responsible for the delivery of the intervention, if it were to be implemented in practice in the future. Therefore, a qualitative focus group study was conducted with the following aim:

(i) To explore the perceptions and experiences of exercise professionals involved in exercise after stroke regarding goal setting.

This study is presented as chapter 8 of this thesis.

3.8. **Chapter conclusion**

The overall aims, and the rationale and aims for each individual study have been outlined. Each of these studies is presented as individual chapters next.

4. STUDY ONE: The effects and experiences of goal setting in stroke rehabilitation – a systematic review

4.1. Introduction

A systematic review of literature on the effects and experiences of goal setting in stroke rehabilitation was undertaken as study one of this programme of work, and is presented in this chapter. This systematic review has been published in the journal 'Disability and Rehabilitation' (Sugavanam et al. 2013) and the article is attached as Appendix 3. In this chapter, the background and rationale for the work are established first, followed by the aims and methods. The results are outlined next and discussed further. Finally, the strengths and limitations of the systematic review are identified.

4.2. Background and rationale

As outlined in section 2.7.4, goal setting is widely recognised as an integral part of rehabilitation, including stroke rehabilitation (Davis et al. 1992, Playford et al. 2009, Wade 2009, Wade and De Jong 2000). Goal setting has also been recommended in the National Clinical Guidelines for Stroke (NICE 2008, NICE 2013, SIGN 2010, Intercollegiate Stroke Working Party 2008) (refer to section 2.7.6 for further explanation). Despite this, there was a lack of integration of evidence specifically related to stroke rehabilitation, as explained in section 2.7.4.4. With current interest in goal setting and with the growing number of studies, a systematic review to integrate all the evidence underpinning goal setting is important. A systematic review can help to determine how goal setting should be used most effectively in clinical practice, to identify key knowledge gaps, and thus areas for new research. In section 2.7.4.4, the rationale for the systematic review was discussed in light of the systematic reviews by Levack et al. (2006a) and Kamioka et al. (2009).

In order to be able to provide recommendations for best clinical practice, it is important to consider both effects and experiences in relation to goal setting. However, there appears to be no systematic review that concentrates specifically on the effects and experiences of goal setting in stroke rehabilitation, with the explicit intention of improving current clinical practice.

4.3. **Aims**

The purpose of this systematic review was to evaluate, critically appraise and synthesise the evidence for the effectiveness of goal setting alongside the experiences of goal setting, in order to identify and put forward recommendations for best practice in stroke rehabilitation.
The two main research questions were:

1. What are the effects of goal setting in stroke rehabilitation on physical function (for example change in performance of activities of daily living) and psychological function (for example changes in self-efficacy and quality of life)?
2. What are the experiences of people affected by stroke and their treating professionals in relation to goal setting?

As presented in section 2.7.1, three different definitions have been identified for goal setting. Although the definition of goal setting by the Intercollegiate Stroke Working Party of the Royal College of Physicians (2008) has been chosen for the thesis, this definition was not used for study identification in this systematic review. The definition by the Intercollegiate Stroke Working Party (2008) emphasises that patients need to be included in the goal setting process. However, in current practice, it is not always clear if this is the case (Leach et al. 2010, Holliday et al. 2005). Therefore, for the systematic review to be as inclusive as possible, it was decided to include studies where study participants were not included in the process of goal setting, or where their involvement was unclear.

Hence, the definition of goal setting by McGrath and Davis (1992) was chosen for this review. McGrath and Davis (1992, p. 226) define goal setting as "a directive activity incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation". This definition was only used for the selection of studies. The results of the included studies were not interpreted based on this definition.

4.4. **Methods**

4.4.1. **Design**

As the aim of the review was to evaluate both the effects and experiences of goal setting, it was necessary to include both quantitative and qualitative studies. As studies from different research paradigms required different types of data synthesis, measures were taken to ensure that appropriate methods of data synthesis were adopted (Harden and Thomas 2005). Based on the recommendation of Jackson and Waters (2005), the framework proposed by Thomas et al. (2004) was used. As per the framework, data from quantitative and qualitative studies were extracted and analysed separately and the findings were then synthesised to answer the research questions (Thomas et al. 2004). This is illustrated in Figure 4.1.

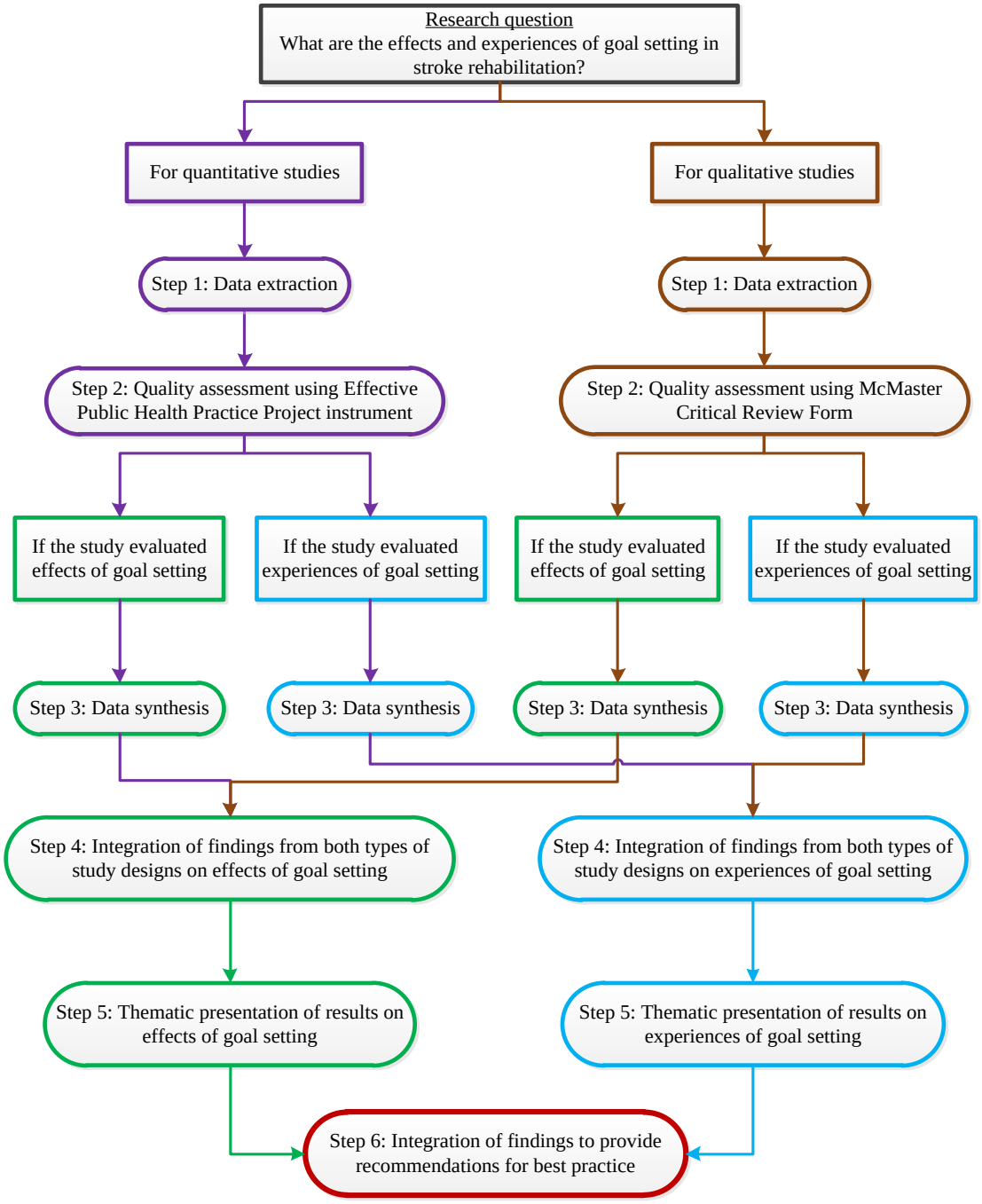

Figure 4.1: Representation of the how the framework of Thomas et al. (2004) **was used in the systematic review**

Key: Purple colour refers to quantitative; brown colour refers to qualitative; green colour refers to effects of goal setting; blue colour refers to experiences of goal setting; red colour refers to final integration.

4.4.2. **Search methods**

The complete holdings of Pubmed, Medline, CINAHL, SPORTDiscus, PsycINFO, British Nursing Index, Web of Science, Cochrane, PEDro, Scopus, REHABDATA, EMBASE and AMED were searched from the start of the database until the end of April 2011 by one reviewer (TS). Current Controlled Trials (www.controlled-trials.com) and the Stroke Trials Directory (www.strokecenter.org/trials/) were also searched until the end of April 2011. The reference lists of the included papers were screened for further relevant publications by the same reviewer.

4.4.3. **Keywords**

Key words relating to 'Stroke' and 'Goal setting' were used (see Appendix 4 for PubMed search strategy). The same key words were modified to suit the other databases.

4.4.4. **Inclusion criteria**

An article was selected for the review if it fulfilled the following criteria:

(i) Studies of any methodological type, as goal setting in stroke rehabilitation is a developing field and it was expected that the number of RCTs may be low.
(ii) Adults (over 18 years of age) affected by any type and duration of stroke.
(iii) Any setting (e.g. hospital, community, day care, home). Studies involving any form of goal setting (e.g. COPM, GAS) and evaluating either the effects and/or experiences of goal setting.
(iv) Studies available in English as a full article.

4.4.5. **Exclusion criteria**

A study was excluded if it met any one of the following criteria:

(i) Full text of article not available in English.
(ii) Audit study without any patient data.
(iii) Not reporting any data on effects or experiences of goal setting.
(iv) Reporting only carer experiences.
(v) Quantitative studies with mixed population (including stroke) when stroke-specific data could not be obtained even after contacting the relevant authors.
(vi) Qualitative design study involving a mixed population (including stroke). Extracting stroke-specific data from these studies would have required analysis of the raw data, which was not within the scope of this review.

4.4.6. **Study selection**

Relevant titles were selected from the full list obtained from the database searches by the principal reviewer (TS)[*]. Duplicates in this list were removed using Reference Manager and the abstracts of remaining studies were scrutinised by the same reviewer, who obtained the full text of potentially relevant studies. These studies were then scored independently by two reviewers (TS and FvW or GM) using a decision tree with inclusion and exclusion criteria (Figure 4.2). Any disagreements regarding study selection were resolved through discussion, after which a final decision on inclusion or rejection was made. A third reviewer (MD) could be consulted in cases where disagreement could not be resolved, however this was not required.

[*]Researcher Thava Priya Sugavanam (TS) is the principal researcher/reviewer and is referred to as 'the researcher' throughout this document. The other researchers are denoted by their initials.

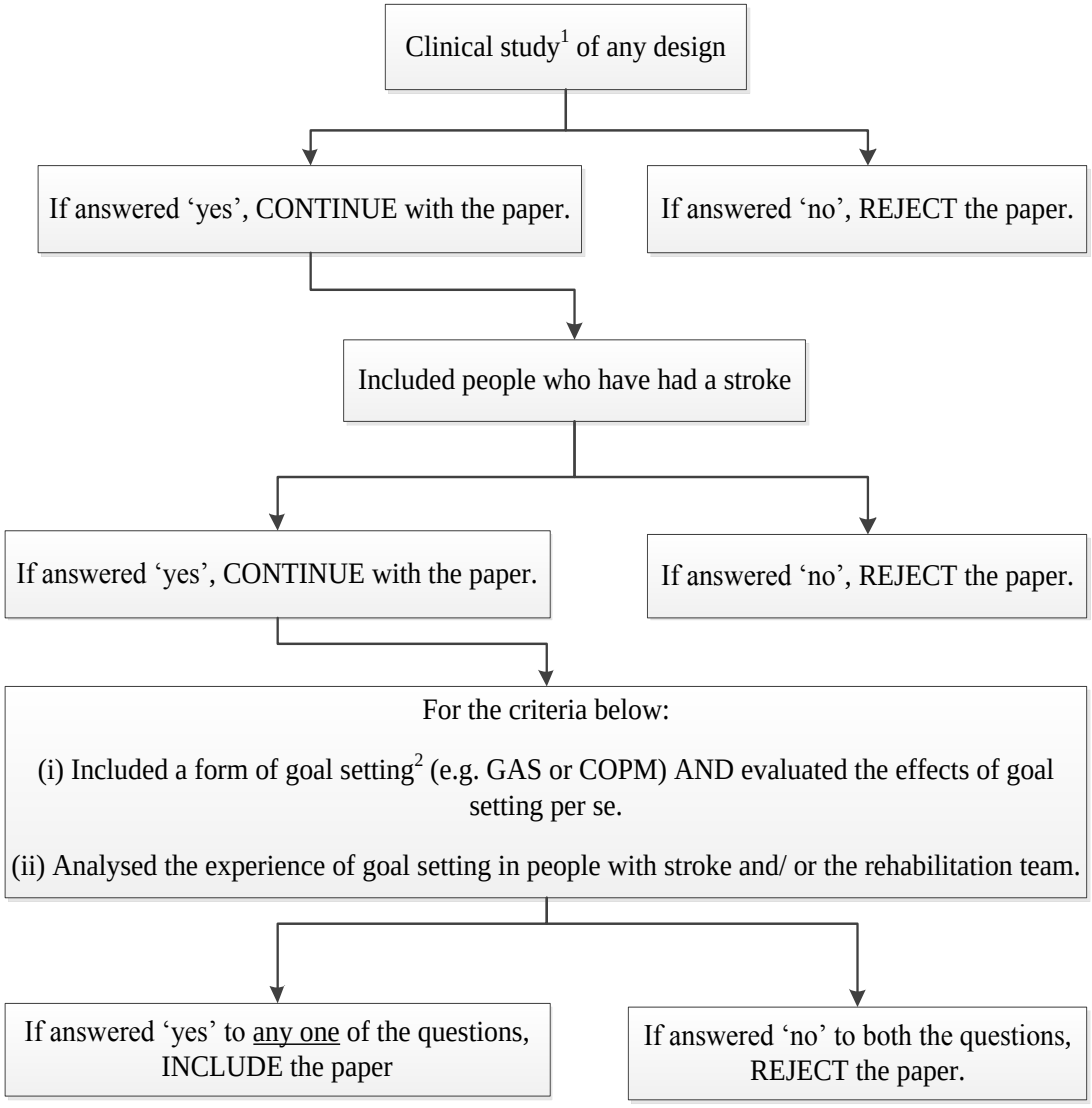

Figure 4.2: Decision tree for selecting abstracts for further scrutiny

Key: [1]Clinical studies included a range of studies, from case studies to randomised controlled trials; [2] Goal setting was defined according to McGrath (1992, p. 226) "a directive activity incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation"; COPM: Canadian Occupational performance Measure; GAS: Goal Attainment Scaling.

4.4.7. **Assessment of methodological quality**

4.4.7.1. Quality assessment of quantitative studies

Since all types of quantitative study designs were included in this review, an assessment tool that could be used for non randomised studies was required for methodological quality assessment. One such tool was chosen for this review as it was designed to encompass a variety of research designs: the Effective Public Health Practice Project (EPHPP) instrument (Thomas et al. 2004).

The members of EPHPP recognised the need for a tool to assess non randomised studies in the public health domain and therefore developed the EPHPP instrument. The developers report that several pilot tests were undertaken, and experts were involved before the tool was finalised, to establish the content validity of the tool (Thomas et al. 2004). Construct validity was established on comparison with component ratings of the Guide to Community Preventive Services instrument by the same authors (Thomas et al. 2004). Moderate to excellent inter-rater reliability has also been demonstrated for this tool (Armijo-Olivo et al. 2012). The EPHPP quality assessment tool has been recommended for use in systematic reviews of effectiveness by other groups of researchers (Jackson and Waters 2005, Deeks et al. 2003). Although the validity studies were conducted by the developers themselves, introducing a source of bias, the recommendation of the tool by other researchers, and its use in more than 35 systematic reviews, justifies the selection of the tool for use in this review.

The EPHPP instrument assesses each study on the following criteria: selection bias, study design, confounders, blinding, data collection method, withdrawals and drop-outs, intervention integrity, and analyses. However, as per the protocol, the last two items were not used to assess the overall ratings. For each of the other six criteria, an individual scoring of ‘strong’, ‘moderate’ or ‘weak’ was provided. The accompanying dictionary was used for the definition of all the criteria and ratings.

Based on the ratings of the six individual items, a global rating was provided for the study as either ‘strong’, ‘moderate’ or ‘weak’. A study was rated ‘strong’ if it had no weak individual ratings; ‘moderate’ if it had one individual weak rating; and ‘weak’ if it had two or more weak individual ratings (Thomas et al. 2004).

The methodological quality of the quantitative studies was assessed by TS and FvW. Following independent review of each article, findings were compared and any discrepancies were resolved through discussion between reviewers. A third reviewer (MD), although available, was not required.

4.4.7.2. Quality assessment of qualitative studies

The McMaster Critical Review Form version 2.0 was used to evaluate the qualitative studies included in the review (Letts et al. 2007a). The section on trustworthiness from the previous version of the form (Law et al. 2002) was also added to enhance quality assessment.

This form is one of the commonly cited checklists for assessing the methodological quality of qualitative studies. Responding to a lack of suitable checklists in this field, the McMaster University Occupational Therapy Evidence-Based Practice Research Group developed version 1.0 of this form based on the best available criteria in 1998 (Law et al. 2002, Scheer et al. 2008). The form was further developed based on peer review, and published as version 2.0 with revised guidelines in 2007 (Letts et al. 2007a, Scheer et al. 2008, Letts et al. 2007b). The modified version has demonstrated good inter-rater agreement of 75-86% (MacDermid and Law 2008). The form has also been used in several systematic reviews to evaluate qualitative studies (Fitzpatrick-Lewis et al. 2010, Shields et al. 2012). Hence the McMaster Critical Review Form was chosen for this systematic review to assess the quality of qualitative studies.

Studies were assessed on study purpose, literature, study design, sampling, data collection methods, data analysis method, conclusions, and implications. The section on trustworthiness from the previous version of the form (Law et al. 2002) was also added to enhance quality assessment. The accompanying guidelines were used for the definition of each criterion (Letts et al. 2007b). Based on the findings, the overall rigour of the study on credibility, transferability, dependability and confirmability was assessed. However, for each of these criteria, a judgment was required as to whether it was met or not. To improve the reliability of this judgement, the reviewers agreed that the study should demonstrate at least half of the ideal study characteristics as described in the accompanying guidelines in relation to that criterion. For example: for the criterion 'credibility' to be satisfied, the study should demonstrate at least three in the below list (i) data from a range of participants, (ii) variety of methods to gather data, (iii) journal of reflection, (iv) triangulation and (v) member checking.

The quality assessment of qualitative studies was undertaken by TS and CB. Following independent review of each article, findings were compared and any discrepancies were resolved through discussion between reviewers. A third reviewer (MD), although available, was not required.

4.4.8. **Data extraction**

A paper data extraction form was designed to extract data on study design, aims; inclusion/ exclusion criteria; sample characteristics; setting, goal setting method; any additional methods employed; any interventions used; goal setting outcome measures; any other outcome measures, and results. Studies were categorised as qualitative, quantitative or mixed methods (i.e. a combination of qualitative and quantitative methods) as specified by study authors. Data were extracted independently by two of three reviewers (TS and either FvW or GM); where any

discrepancies were detected, differences were resolved through discussion. A third reviewer (MD), although available, was not required.

4.4.9. **Data synthesis**

A quantitative meta-analysis using standardised mean differences (Higgins and Green 2011) was originally proposed for the quantitative studies. However, following data extraction, it turned out that this was not possible due to the high variability in design, methods of goal setting and outcome measures employed in the studies. Therefore, the findings from each study were grouped, based on study aims and outcomes. These findings were synthesised and presented as themes.

For the qualitative studies, a thematic synthesis was undertaken (Thomas and Harden 2008), for which the main findings relating to the research questions were labelled and coded. These initial ideas were then analysed and grouped into themes by TS, and then verified by FvW and CB.

4.5. **Results**

4.5.1. **Process of study selection**

From a total of 53,998 hits, 112 full text articles were selected for analysis, from which 17 were selected to be included in the review. A schematic representation of the study selection process is presented as Figure 4.3.

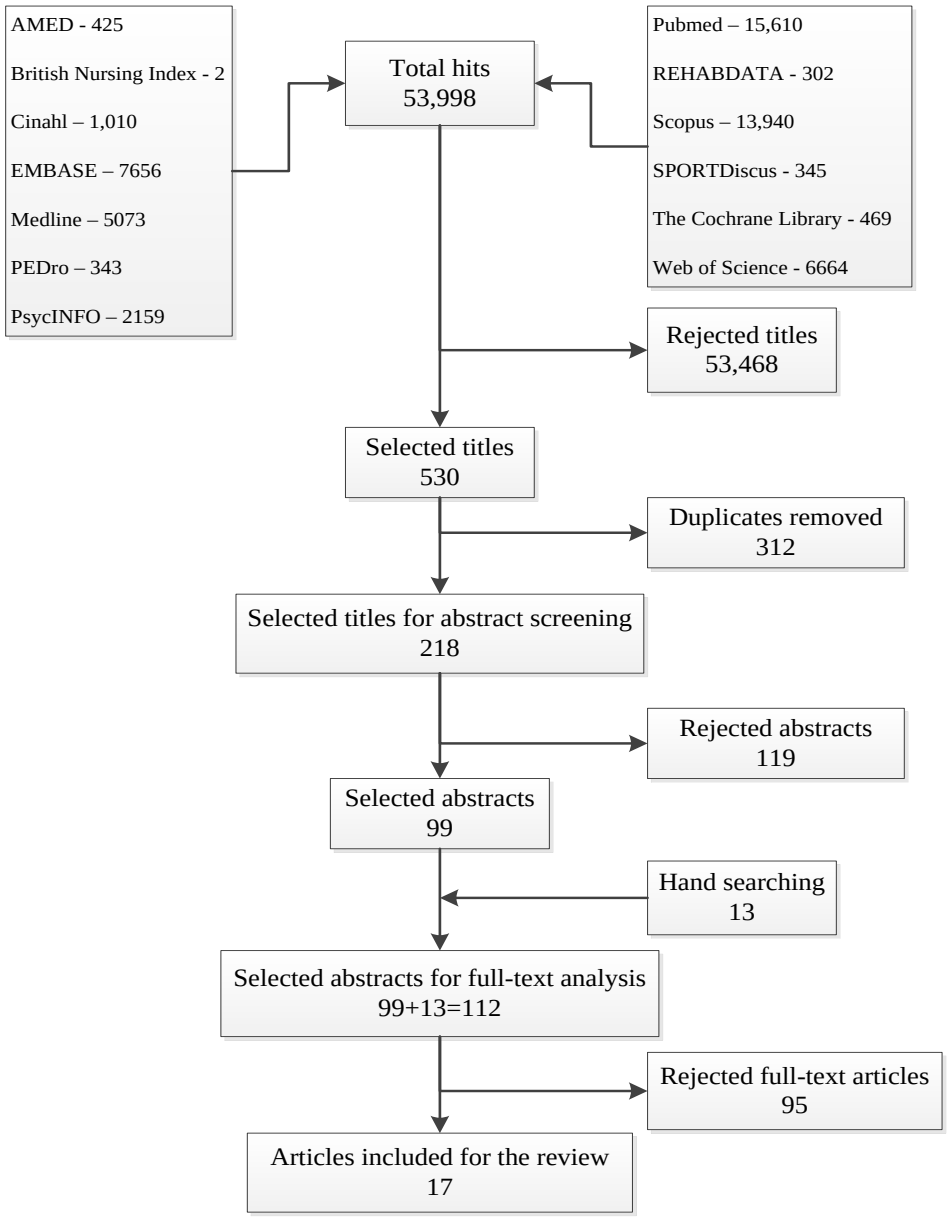

Figure 4.3: Schematic representation of the study selection process

4.5.2. **Excluded studies**

On full text analysis of 112 articles, 95 studies were rejected as five were not in English, 16 were not clinical studies, 11 studies did not include stroke patients, six did not use any goal setting methods, 17 studies did not evaluate effects or explore experiences of goal setting (instead evaluated effects of non-goal setting

interventions), authors did not respond to the request for stroke-specific data in nine studies, authors responded that stroke-specific data were not available for two studies, 10 studies had only evaluated the psychometric properties of goal setting outcome measures, eight studies had used goal setting measures such as COPM and GAS but as outcome measures only, and 11 studies were qualitative with a mixed population. The excluded studies and the reasons for rejection, along with the references, are outlined in Appendix 5.

4.5.3. **Description of included studies**

Of the 17 included studies, 11 (64.7%) were quantitative, none of which was an RCT (Almborg et al. 2009, Black et al. 2010, Brock et al. 2009, Folden 1993, Jansa et al. 2004, McAndrew et al. 1999, Phipps and Richardson 2007, Reid and Chesson 1998, Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a). Six (35.3%) were qualitative studies (Leach et al. 2010, Wressle et al. 1999a, Hale 2010, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996). Seven studies evaluated the effects of goal setting (Black et al. 2010, Brock et al. 2009, Folden 1993, Phipps and Richardson 2007, Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a), and ten studies explored the experiences of goal setting (Leach et al. 2010, Wressle et al. 1999a, Almborg et al. 2009, Jansa et al. 2004, McAndrew et al. 1999, Reid and Chesson 1998, Hale 2010, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996). A total of 614 participants with stroke were involved in the studies, along with 43 professionals and 38 carers. The average age and gender of the included participants could not be calculated, as most of the qualitative studies did not provide this information. The stroke characteristics were also not provided in most of the studies.

4.5.4. **Methodological quality**

4.5.4.1. Methodological quality of quantitative studies

The methodological quality of the quantitative studies is presented in Table 4.1. Of the 11 quantitative studies, only two had a rating as ‘strong’ (Brock et al. 2009, Jansa et al. 2004), five studies were in the category of ‘moderate’ (Almborg et al. 2009, Black et al. 2010, Folden 1993, Phipps and Richardson 2007, Reid and Chesson 1998) and four were in the ‘weak’ category (McAndrew et al. 1999, Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a) on the EPHPP instrument.

The study design had an impact on the other criteria such as blinding, resulting in a lower global rating. However, the two studies which had a ‘strong’ design (Folden 1993, Wressle et al. 2002a) fell short in other categories such as confounders and therefore did not have a ‘strong’ overall rating. For some studies, certain factors that were intended (e.g. having two different participant groups (therapists and patients) in the study of McAndrew et al. (1999)), contributed to an overall ‘weak’ rating rather than a reflection of how the study was conducted.

Table 4.1: Methodological assessment of the quality of quantitative studies using the Effective Public Health Practice Project instrument (Thomas et al. 2004)

Key: * denotes quantitative studies evaluating the experiences of goal setting

Author &year	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals & drop-outs	Global rating
Almborg et al. (2008)*	Moderate	Moderate	Not applicable	Weak	Strong	Moderate	**Moderate**
Black et al. (2010)	Moderate	Moderate	Not applicable	Moderate	Weak	Strong	**Moderate**
Brock et al. (2008)	Moderate	Moderate	Not applicable	Moderate	Strong	Moderate	**Strong**
Folden (1993)	Moderate	Strong	Weak	Moderate	Strong	Moderate	**Moderate**
Jansa et al. (2004)*	Moderate	Moderate	Not applicable	Moderate	Strong	Strong	**Strong**
McAndrew et al. (1999)*	Strong	Weak	Not applicable	Weak	Weak	Strong	**Weak**
Phipps and Richardson (2007)	Moderate	Weak	Not applicable	Moderate	Strong	Not applicable	**Moderate**
Reid and Chesson (1998)*	Moderate	Weak	Not applicable	Moderate	Strong	Strong	**Moderate**
Schweizer et al. (2008)	Weak	Weak	Not applicable	Weak	Strong	Strong	**Weak**
Wilson et al. (2002)	Weak	Weak	Not applicable	Weak	Weak	Strong	**Weak**
Wressle et al. (2002)	Moderate	Strong	Weak	Moderate	Weak	Weak	**Weak**

4.5.4.2. Methodological quality of qualitative studies

The methodological quality of the six qualitative studies reflected both the internal and the external validity of the studies, as evident from the Table 4.2. All six studies showed evidence of credibility (Leach et al. 2010, Wressle et al. 1999a, Hale 2010, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996), four showed evidence of transferability (Leach et al. 2010, Wressle et al. 1999a, Hale 2010, Mew and Fossey 1996), five showed dependability (Leach et al. 2010, Wressle et al. 1999a, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996) and only two showed evidence of confirmability (Leach et al. 2010, Mew and Fossey 1996).

Clear aims, good description of data collection methods and appropriate conclusions were evident in all the studies. On the other hand, failure of most of the authors to describe the theoretical perspectives, the underlying assumptions of researchers, and how the researcher's relationship with the participants and their role in the data collection could have influenced the results, reduced the transparency of the findings and thereby the overall rigour.

Table 4.2: Methodological assessment of the quality of qualitative studies using the McMaster University Critical Review Form

(Letts et al. 2007a)

Key: ccn: Clinical case notes; fn: field notes; GT: Grounded Theory; Eth: Ethnography; ID: Interpretative description; in-d: intervention diaries; int: interviews; nad: not addressed: n/a: not applicable; npo: non participant observation; obs: video & audio observation; sr: analysis of structured records; ✓: yes; ×: no.

Author and year	Study purpose	Literature review	Study design	Theoretical perspective	Methods used	Sampling		Informed consent	Descriptive clarity				Procedural rigour	Inductive data analysis	Findings consistent with data	Reporting of decision trails and audit	Transforming data into themes/codes	Theoretical connections	Triangulation				Member checking	Appropriate conclusions	Contribution for further research	Credibility	Transferability	Dependability	Confirmability
						Purposeful selection	Sampling until data redundancy		Site	Participants	Role of researcher & participant relation	Identification of assumption of researcher							Sources	Methods	Researchers	Theories							
Hale (2010)	✓	✓	ID	×	int, ccn, npo	✓	×	✓	✓	✓	✓	×	✓	✓	✓	×	×	✓	×	✓	×	×	✓	✓	✓	✓	✓	×	×
Laver et al. (2010)	✓	✓	nad	×	int, ccn	✓	✓	✓	✓	✓	✓	×	×	✓	✓	×	×	✓	✓	✓	✓	×	×	✓	✓	✓	×	✓	×

Lawler et al. (1999)	✓	✓	GT	✓	int, sr	✓	×	✓	×	×	×	×	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	×	✓	×
Leach et al. (2010)	✓	✓	nad	×	e-mail int	✓	×	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mew and Fossey (1996)	✓	✓	Eth	×	obs, int, fn	✓	n/a	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Wressle et al. (1999)	✓	✓	GT	✓	int, in-d	✓	✓	nad	✓	✓	×	×	✓	✓	✓	×	✓	✓	✓	✓	×	✓	×	✓	✓	✓	✓	✓	×

4.5.5. **Definition, theories and methods of goal setting**

The majority of the studies did not explicitly define goal setting or state the theories underpinning their goal setting intervention. The SCT, Goal Setting Theory and Self-Regulation Theory were mentioned in three studies (Leach et al. 2010, Brock et al. 2009, Laver et al. 2010). Goal setting was approached through different perspectives, such as client-centred practice, cognitive rehabilitation and goal attainment. This may have led to the development of different goal setting methods, evident in the included studies (Table 4.3 and Table 4.4).

4.5.6. **Effects of goal setting**

Seven studies, involving 332 people with stroke and 23 carers, used a form of goal setting and evaluated its effects (Table 4.3). 202 males and 153 females were included with an average age of 57.7 years.

The study design and methods of goal setting varied among the studies (Table 4.3). Of the seven studies, two were quasi-experimental studies (Folden 1993, Wressle et al. 2002a), three were cohort studies (Black et al. 2010, Brock et al. 2009, Phipps and Richardson 2007), and two were single case studies (Schweizer et al. 2008, Wilson et al. 2002). As for the methods of goal setting, the COPM was employed in two studies (Phipps and Richardson 2007, Wressle et al. 2002a), while GAS was used in the study by Brock et al. (2009). Goal management training featured in one single case study (Schweizer et al. 2008) and goal planning in another single case study (Wilson et al. 2002). Folden (1993) used goal setting in the form of a supportive educative nursing intervention, while Black et al. (2009) outlined a goal setting system that had been practised within their rehabilitation team.

Table 4.3: Overview of studies included in this review, evaluating the effects of goal setting as an intervention

Key: C: carer/ family; CES-D: Centre for Epidemiologic Studies Depression Scale; CG: control group; COPM: Canadian Occupational Performance Measure; COPM-P: Performance dimension of the COPM; COPM-S: Satisfaction dimension of the COPM; COVS: Clinical Outcome Variables; EG: experimental group; ESCA scale: Revised version of the Exercise of Self-care Agency scale; FIM: Functional Independence Measure; GAS: Goal Attainment Scaling; GS: goal setting; HCP: health care professionals; LHS: London Handicap Scale; LOS: length of stay; (M)MMSE: (Modified) Mini Mental State Examination; OT: Occupational therapy/ therapist; PADL: Personal ADL; PT: Physiotherapy/ therapists; PWS: person (s) with stroke; SALT: Speech and Language Therapy/ therapist; SUPPH: Strategies used by People to Promote Health, TBI: Traumatic brain injury.

Author (year) Country	Study design	Sample size	Goal setting method & details Measures collected when?	Findings related to goal setting
Black et al. (2010) Australia	Prospective observational study	Total sample size n=54 PWS n=26	Goals set in various domains with contributions from all rehabilitation team members. Goal achievement scored as 'exceeded', 'achieved' or 'not achieved'. Measures taken at two weeks after initial team meeting and at discharge.	Significant correlations between short-term goal achievement at two weeks post initial team meeting and achievement of discharge goals for global function (rho = 0.67 $p < 0.001$). For those returning home, correlation between predicted and actual LOS: $r = 0.71$, $p<0.001$. Significant correlations between adherence to predicted LOS and achievement of short-term goals in transfers (rho = 0.45, $p = 0.04$), PADL (rho = 0.44, $p = 0.04$) and global function (rho = 0.62, $p < 0.01$).

Brock et al. (2008) Australia	Prospective follow-up cohort study.	Baseline: PWS n=59 Follow-up at six months post discharge: PWS (from original sample) n=45 & C n=23.	GAS, using median instead of weighted scores. Patients and carers involved in GS and all team members trained in GS. Measurements done prior to in patient discharge and at six months post-discharge.	Goal attainment at six months post-discharge: 21/45 cases (47%) achieved all goals; 16/45 cases (36%) made some progress; 8/45 cases (17%) made no progress or deteriorated. Moderate correlation between goal attainment and LHS (between -0.45 and -0.51, $p<0.005$) at six months post-discharge on LHS ($-0.52\leq rs \leq -0.47$, $p<0.005$). Significant correlation at six months post discharge and not at discharge between goal attainment and FIM-Motor ($rs = 0.55$, $p<0.001$), SUPPH-coping ($rs = 0.43$, $p<0.005$), CES-D ($rs = -0.43$, $p<0.005$).
Folden (1993) USA	Quasi-experimental study.	Baseline: PWS n=90 Post test (14 to 18 days after baseline): PWS (from original sample) n=68 (34 in each group)	GS only in EG. Intervention protocol involved helping the participant identify, clarify expressing goals in measurable terms, identify and list self-care assets needed and self-care deficits that must be overcome to meet goals, identify strategies to meet goals. Four visits at least two days apart over a four week period in addition to regular rehabilitation. Control group received regular rehabilitation but had no contact with the researcher. Pre-test measurement three to four days after admission to unit and post-test 14 to 18 days after administration of the pre-test.	EG (mean score 127.74) improved significantly more than CG (mean score 115.18) in the perception of self-care ability as measured on ESCA ($F=33.36$, $p<0.001$).

Phipps and Richardson (2007) USA	Retrospective cohort study.	Total sample size n=155. PWS n=117 in which n=53 right hemisphere stroke and n=64 left hemisphere stroke.	COPM. Patients along with the treating team involved in the GS process. Family member or translator involved if required. Therapists trained and assessed on the COPM. COPM scores calculated at the start of the OT intervention and at discharge.	Goal attainment: Significant changes on COPM ($p<0.05$) post-intervention. Change in mean COPM-P (SD) - PW(right)S: 3.71 (2.12), PW(left)S: 2.85 (2.14); Change in mean COPM-S (SD) - PW(right)S: 4.07 (2.41), PW(left)S: 3.00 (2.31). PW(right)S had significant increase in COPM-S than PW(left)S ($p=0.03$).
Schweizer et al. (2008) Canada	Uncontrolled single case study as part of RCT.	PWS n=1	Goal Management Training (GMT). GMT uses task breakdown, self-prompting to halt automatic behaviours that impede progress, resuming control and monitoring progress with a task, to overcome disorganised behaviour. GMT consisted of 2-hour sessions once per week for 7 weeks. Measurements taken at baseline (127 days post-injury), post-intervention (after seven weeks – 218 days post-injury) and four months after intervention (322 days post-injury).	Generic goal of GMT: to reduce disorganised behaviour stemming from executive and attentional impairments. Improvements on a range of neuropsychological tests, including memory, verbal learning, and attention tasks. Return to work.

Wilson et al. (2002) UK	Single case study, pre-test post-test design.	PWS n=1	Goal Planning. A total of 12 goals were set, tailored to the individual covering all domains of the WHO ICF. Long-term goals were broken down into one or two short-term goals. Goals agreed between participant, spouse and members of rehabilitation team. Measures taken at start, throughout, and end of the 100-day intervention and on three occasions afterwards up to one year after end of intervention.	Goal attainment: all goals achieved – although cognitive impairments persisted, and performance on many of the goals identified lower than normal. Achievements at discharge were maintained until one year post-intervention.
Wressle et al. (2002) Sweden	Experimental design with experimental (COPM) and control group.	Total sample size n=206 PWS n=50 in EG (of which n=28 interviewed) & n=24 in CG (of which n=11 interviewed)	Goal setting using COPM in the EG. Patients and therapists involved in the GS process Measures taken on admission and prior to discharge. Structured interviews within two to four weeks after discharge.	No significant differences between groups on the Klein-Bell ADL scale and COVS. Significant improvement on COPM-P ($Z= -5.935$, $P<0.001$) and COPM-S ($Z= -5.775$, $P<0.001$) scores on discharge in the EG. Average change score for COPM-P was 3.13 and 3.29 for COPM-S denoting clinical significance. Interview findings: agreement that goals were formulated for treatment (82% in EG, 27% in CG); recall of own treatment goals (72% in EG, 36% in CG); perceived active participation in goal formulation process (46% in EG, 9% in CG); managing more tasks compared to before rehabilitation (75% in EG, 9% in CG).

The findings from the seven studies have been synthesised and presented as themes below.

4.5.6.1. Effects on recovery

The effects of goal setting on recovery were explored in four studies (n=193 participants with stroke) (Phipps and Richardson 2007, Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a), of which three were of a 'weak' quality (Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a) and one study was of 'moderate' quality (Phipps and Richardson 2007) (Table 4.1).

In both studies where the COPM was used, performance and satisfaction scores improved significantly at discharge, implying goal achievement and thereby recovery (Phipps and Richardson 2007, Wressle et al. 2002a). Interestingly, participants with right hemisphere strokes had greater increases in satisfaction than left hemisphere stroke participants in the study of Phipps and Richardson (2007). The authors suggested that this finding may be attributed to the finding from the literature that greater impairment of self-awareness is associated with right hemisphere strokes and higher depression with left hemisphere strokes. Neither of these suggestions was verified in the study cohort, however.

Similarly, goal management training (GMT) and goal planning approach applied in two single case studies (n=2 participants with stroke) had positive results for goal achievement, indicating recovery (Schweizer et al. 2008, Wilson et al. 2002). However, neither of these studies provided more information on goal setting.

Schweizer et al. (2008) used GMT in a male individual with executive dysfunction, initiated at approximately four months following a right-sided cerebellar stroke. Other than general principles, there was little information on the precise content or process of the GMT intervention in this paper, and there was no evidence that the patient had been

involved in the process. The effects of GMT were assessed using a battery of tests of attention and executive function, administered before, immediately after and four months after completion of the GMT. Improvements were noted in a number of outcomes. In functional terms, the patient was able to return to work, while his spouse noted that the symptoms of executive dysfunction had disappeared (Schweizer et al. 2008).

In the second single case study, the authors detailed a goal planning approach in the cognitive rehabilitation of a male individual with bilateral stroke, in conjunction with a severe head injury following a road traffic accident (Wilson et al. 2002). The method of goal planning was detailed and involved assessment of the patient in the home and work environment, identification of problem areas and agreement of long term goals between the patient, his spouse and the rehabilitation team. There was no indication, however, on how goals were negotiated, reviewed, whether they were adjusted in the course of the intervention and what difficulties – if any – were encountered along the way, especially since the patient appeared to have communication difficulties. In terms of the effectiveness of this programme as a whole, the patient was described as having achieved all his goals at discharge. However, what was not entirely clear from the data was to what extent each of the goals was achieved; the authors acknowledged that some of the long term goals were lacking in specificity (e.g. "increase intelligibility of speech"). Given the patient's apparent difficulties with communication, it would also have been of interest to understand how goals were agreed, what barriers were encountered in the process and how these were resolved.

4.5.6.2. Effects on participants' perceived self-care ability and engagement in rehabilitation

The effects of goal setting on participants' perceptions were analysed in two quasi-experimental studies (n=142 participants with stroke) (Folden 1993, Wressle et al.

2002a). When participants were supported to identify, clarify and express goals, and develop strategies to achieve goals in the domain of self-care in a study of 'moderate' quality (Table 4.1), their perceptions of self-care ability improved when compared with participants who did not have this added intervention (Folden 1993). However, it was not clear whether perceptions of self-care ability were mirrored by actual behavioural outcomes.

In another study of a 'weak' methodological rating (Table 4.1), participants who were involved in goal setting were able to recall their treatment goals better, and manage more tasks, compared to a group that did not participate in goal setting (Wressle et al. 2002a). However, several methodological limitations were evident in this study. Firstly, there were only 24 participants with stroke in the control group, compared with 50 participants with stroke in the experimental group. Secondly, the experimental group demonstrated significantly lower function in ADL at baseline. Thirdly, the experimental group received significantly more treatment focused on physical function than the control group, which may have influenced their perceptions of self management. These significant differences between the groups may have confounded the findings. This study would therefore warrant replication in a rigorously designed RCT.

4.5.6.3. Correlations of goal setting outcomes with other variables

Goal achievement was correlated with other variables in two studies (n=71 participants with stroke and 23 carers) (Black et al. 2010, Brock et al. 2009): one with a 'strong' methodological rating (Brock et al. 2009) and one with a 'moderate' methodological rating (Black et al. 2010) (Table 4.1).

Based on the findings, Black et al. (2010) concluded that short term goal attainment could be used to measure progress and that the assessment could also aid the treating team in reviewing rehabilitation plans (Table 4.3). However, the results may have been

influenced by the short time span between the setting of goals (at two weeks) and discharge (from three weeks). With the focus of the study on short-term goal attainment, it was surprising to note that short-term goals were not routinely discussed with patients in this study, as they were viewed as stepping stones towards discharge goals. This raises questions as to whether the participants understood the linking between short-term and long-term goals and what short-term goal attainment meant to the participants.

In the study by Brock et al. (2009), correlations between goal attainment and perceived level of participation, motor ability, self-efficacy and depression were evaluated. Although no significant correlations between goal attainment and the above measures were found when assessed prior to discharge, goal attainment showed a moderate to strong correlation with these measures at six months post-discharge (Table 4.3). Therefore, the authors speculated that, instead of factors such as depression and self-efficacy at discharge influencing goal attainment at a later stage, goal attainment itself might effect positive changes in mood, physical ability and self-efficacy. However, this was only speculation and these results need to be confirmed with a bigger sample, and validated outcome measures.

4.5.7. **Experiences of goal setting**

Ten studies involving 282 participants with stroke, 15 carers and 43 HCPs explored experiences of goal setting (Table 4.4). Four were quantitative (Almborg et al. 2009, Jansa et al. 2004, McAndrew et al. 1999, Reid and Chesson 1998) and six were qualitative (Leach et al. 2010, Wressle et al. 1999a, Hale 2010, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996). For this sub-group, the average age, gender and other stroke characteristics could not be calculated as most of the studies did not provide this information. Due to the varied design and outcomes of the quantitative studies, a quantitative synthesis was not possible. Therefore, the main findings of these four quantitative studies were integrated with the themes that emerged from the analysis of qualitative studies and are presented together.

Table 4.4: Overview of studies included in the systematic review, exploring the experiences of goal setting.

Key: ADL: Activities of Daily Living; C: carer/ family; COPM: Canadian Occupational Performance Measure; COPM-P: Performance dimension of the COPM; COPM-S: Satisfaction dimension of the COPM; EG: experimental group; GAS: Goal Attainment Scaling; GS: goal setting; HCP: health care professionals; (M)MMSE: (Modified) Mini Mental State Examination; OT: Occupational therapy/ therapist; PT: Physiotherapy/ therapists; PWS: person (s) with stroke; SALT: Speech and Language Therapy/ therapist.

Author (year) Country	Study design	Sample size	Data collection method (goal setting method, where relevant) & details	Findings related to goal setting
Almborg et al. (2008) Sweden	Quantitative design: Cross-sectional study	PWS n=188	GS as part of discharge planning. Patients' Questionnaire on Participation in Discharge Planning data collected 2-3 weeks after discharge.	Participants (in %) who perceived participation in discussions on: treatment goals with physician: 29%; goals of further care/ services after discharge: 17%; goals of further rehabilitation after discharge: 15%. Factors associated with greater perceived participation in needs assessment and GS: lower level of ADL at 5 days, higher level of ADL at 2-3 weeks (most important factor), education higher than elementary, longer hospital stays.

Hale (2010) New Zealand	Qualitative design: Interpretative description.	PT's n=4	Method of GS: GAS. The PTs were new to GAS and received training before the start of the study. Multiple data sources: interviews over telephone and in person, PTs' case notes, researcher's field notes and non-participant observation.	(i) Enthusiastically cautious on using GAS: beneficial, not appropriate for all, reliability of GAS questioned, best used with a standardised outcome measure; (ii) Another useful tool in the box of interventions: to guide treatment, to set patient-centred goals, use goals to encourage, motivate and prompt patients; (iii) Time consuming: more time required to set goals; (iv) Not easy to set goals: in case of rapid progress, cognitive or communication disorders, patient's lack of motivation or reluctance to set goals .
Jansa et al. (2004) Slovenia	Quantitative design: Cohort study with pre-post-test measures.	PWS n=80, of whom n=29 used the COPM.	Method of GS: COPM COPM undertaken in: n=26/80 PWS at admission and discharge; n=3/80 PWS at discharge only; n=2 C involved in interview.	Client priorities followed only in 36.25% of the total sample (29 out of 80). Goal attainment: changes in mean COPM scores (range): COPM-P: +2; from 3.6 (1-8) to 5.6 (3-10) (p=0.084); COPM-S: +2; from 4.1 (1-10) to 6.1 (3-10) (p=0.006) Other findings: Not possible to complete the COPM with all participants, due to cognitive, emotional and communicative difficulties (proportion not reported).

Laver et al. (2010) Australia	Qualitative study with semi-structured interviews.	PWS n=15	Semi-structured interviews conducted by the researcher with participants when in the acute hospital care, during sub-acute rehabilitation and six months after stroke. Interview on: setting goals, meaning of the goals, key things that the patients aim to improve, whether they were ready to set goals at each stage in hindsight.	(i) Participant goals: difficulty understanding 'goal' terminology, broad goals rather than specific; (ii) Involvement in GS: unable to recall discussion of specific goals discussed with therapists, most agreed with documented goals & that goals were set with them collaboratively, all participants had at least one goal documented by clinicians in the progress notes; (iii) Readiness to set goals: varied greatly, 7/15 felt not ready to set goals in acute phase, others were ready (6 /7 were able to give at least one goal statement in the acute phase), varied response when participants were asked at six months after stroke as to the best time to set goals, 9/15 lacked knowledge around stroke recovery and unsure as to what goals would be realistic.
Lawler et al. (1999) UK	Qualitative study with semi-structured interviews in context of main study (RCT).	PWS n= 30 C n=15 Specialist nurses n=5.	Information gathered: semi-structured interviews with PWS and C; analysis of structured nurses' records; semi-structured interviews with nurses. The authors conducted the interviews.	Nurses' perceptions: Variable acceptance of the term "goal", some reluctant to use it, due to its association with formality, simplicity and fixed nature; agreement on the individual nature of goals, a collaborative approach, the importance of appropriate goals; difficulties with setting (achievable) goals; perceived danger of interfering with positive relationship; tension between establishing a supportive relationship and motivating patients, and the reality of achievable goals. PWS and C perceptions: formulated hopes rather than specific goals.

Leach et al. (2010) Australia	Qualitative design with semi-structured interviews.	Treating therapists n=8 (n=2 SALT; n=3 OT, n=3 PT) PWS n=5 only as case examples	Qualitative, semi-structured email interviews, based on questionnaire with seven open questions. Framework approach. Email exchanges continued until all necessary data had been obtained and clarified.	GS approaches: Therapist controlled (10/15), Therapist led (4/15), Patient focussed (1/15). Number of barriers outnumbered facilitators. Facilitators to patient-centred GS: generally seen as beneficial in terms of increasing patient motivation and therapist effectiveness, enabling a more holistic rehabilitation process. Barriers to GS: patient factors: communication impairments, depression and grief reactions, unrealistic expectations, lack of insight, cultural and linguistic diversity; therapist factors: lack of time; contextual factors: difficulty setting participation-based goals in sub-acute setting.
McAndrew et al. (1999) USA	Quantitative design: Quasi-experimental between group design.	PWS n=10 OT n=10	GS method: not stated. Questionnaires consisting of matched items developed specifically for the study (one each for patients and therapists). Questions addressed primary roles, interests, hobbies, daily routines, assistance available at home, home environment, and the GS process. Responses to questions were rated on a 5 point Likert scales.	For 9/10 items, the patients' perceptions of the level of collaboration were lower than that of the therapists. Differences statistically significant only in regards to discussion of interests and hobbies ($t=3.16$, $df=18$, $p<.05$), therapists' awareness of assistance available upon discharge ($t=3.49$,$df=18$, $p<.05$) and explanation of the tasks, activities or exercises performed ($t=3.28$, $df= 18$, $p<.05$). Absolute agreement between PWS &OT on whether important activities were included in the goals.

Mew and Fossey (1996) Australia	Qualitative single case study.	OT n=1. (PWS n=1 as case example)	GS method: COPM COPM interview (40 minutes) between OT and patient recorded (video and audio). Also observed by author from another room and field notes taken. A week later, author had a discussion with OT reflecting on clinical reasoning and the COPM interview (audio-taped).	Collaboration between therapist and client is key in the process of GS. The extent to which the patient is involved in their GS process may vary across the stages of the GS process (i.e. defining problems, establishing priority and negotiating goals). Inconsistencies in the collaborative approach with a patient and inability to clearly explain the link between the therapist's and the patient's goals may affect the patient-therapist relationship.
Reid and Chesson (1998) UK	Quantitative case studies Acceptability and feasibility study	PWS n=5 (of 16 PWS, goals were set only for 5 because of many being dysphasic and staffing problems).	GS Method: GAS Therapists' goals: Treating PT assessed the patient and set goals separately using GAS Patients' goals: PWS set goals separately with the help of a different PT who was not involved in the treatment and blinded to treating PT's goals. On GAS completion, the patient read and accepted them.	PWS identified 23 goals, PTs identified 28 goals. Broad agreement between PWSs and PTs regarding main problems for intervention. PWS tended to focus on function, PTs tended to focus on underlying impairments. Goal attainment: PWS reported no improvement in 11/23 goals; PTs reported no improvement in 6/28 goals. Two case studies are reported to highlight differences in GS process and outcomes - goal identification: some goals were identified by PWS that were not identified by the PT, and vice versa; goal scaling differed; level of goal attainment differed.

Wressle et al. (1999) Sweden	Qualitative design with interviews.	The GS component of the paper comprised n=30 interviews with: PWS: n=5, PTs: n=5, OTs: n=5 & Physicians: n=5	From this paper, only the information pertaining to GS was selected, which involved the analysis of 30 interviews. The interviews were conducted by the author at an early stage of rehabilitation process and within 2 weeks of discharge. The interviews focussed on patient's pre-stroke situation, the falling ill period, the rehabilitation interventions, the goals and the method for outcome measuring.	Goals selected by PWS focused on: ADL, attaining pre-stroke status, living at home, regaining mobility and social integration. One patient had no goals. Goals selected by HCPs concentrated on disability and handicap. There were no impairment-orientated treatment goals although there were impairment-orientated interventions. Formulations that did not match the ICIDH were those related to motivation, feelings of security and belief in oneself. Goal attainment- PWS tended to compare their current status with that before stroke; rehabilitation professionals compared the patient's current status with goals set.

4.5.7.1. Goal setting: differences between patients and professionals

Eight studies (n=253 participants with stroke, 15 carers and 35 HCPs) of varying methodological ratings discussed differences within goal setting between patients and professionals (Leach et al. 2010, Wressle et al. 1999a, Almborg et al. 2009, McAndrew et al. 1999, Reid and Chesson 1998, Hale 2010, Laver et al. 2010, Lawler et al. 1999). The quantitative studies had moderate to weak methodologies, while the qualitative studies - excluding the study of Leach et al. (2010) - lacked confirmability (Table 4.1 and Table 4.2).

Patients were often unclear about the meaning of goal setting and their role in this process (Almborg et al. 2009, McAndrew et al. 1999, Reid and Chesson 1998, Laver et al. 2010). Therefore, they had a poorer perception of their participation in goal setting as well as the collaborative process itself, when compared with the positive perceptions of professionals regarding all aspects of goal setting (McAndrew et al. 1999, Reid and Chesson 1998, Hale 2010, Lawler et al. 1999). The findings of Almborg et al. (2009) could be cited as an example to reflect the patients' perceptions of goal setting. In this study, although the majority of participants indicated they had received sufficient information related to discharge planning, their perceptions and involvement in other discussions were low. Only 29% felt they had been able to discuss treatment goals with their physician, only 15% felt they had participated in discussions about rehabilitation and only 38% felt they had participated in discussions about care/ services after discharge (Almborg et al. 2009).

One reason for the lower level of participation could be that patients were not ready to set goals at that particular stage (Laver et al. 2010). In that study, when participants were asked about the right time to set goals, individual variations were seen. Seven out of 15 participants said that they were not ready in the acute stage, although six out of these seven were able to formulate goals. The study further highlighted the need for HCP's to avoid assuming that patients are ready for goal setting.

Patients tended to be more optimistic than therapists regarding the expected level of outcome and this led to patients perceiving lower goal attainment (Reid and Chesson 1998, Lawler et al. 1999). In the study by Reid and Chesson (1998), when patients and therapists set goals and documented goal attainment individually, patients reported no improvement in 11/23 goals, whereas the therapists reported no improvement in only six of the 28 goals. The lower perception of goal attainment among patients could also be attributed to the finding that rehabilitation professionals compared the patients' current status with their most recent post-stroke status, in contrast to the patients, who compared their current with their pre-stroke status (Wressle et al. 1999a).

The differences in perceptions of goal setting between patients and professionals could relate to the goal setting approach used. In the study by Leach et al. (2010), only one therapist (out of 15) fully involved patients in all aspects of goal setting, such as introducing the concept of goal setting early on, asking the patient what they would like to achieve, and involving the patient in goal negotiation. Of the remaining therapists, ten involved patients to some extent by using formal assessments and discussions with patients to inform goal setting, while four professionals drove the process themselves, with limited patient interaction (Leach et al. 2010).

The patients and professionals also differed in the types of goals set (Leach et al. 2010, Wressle et al. 1999a, Reid and Chesson 1998, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996). Patients formulated hopes rather than goals, and any goals formulated tended to be broad, rather than specific (Laver et al. 2010, Lawler et al. 1999). Their goals focused on attaining pre-stroke status, living at home, regaining mobility, improving gait, social integration and undertaking ADL (Wressle et al. 1999a, Reid and Chesson 1998). While patients tended to formulate more general, functional goals for the longer term, therapists tended to identify the underlying short-term

impairment problems. The goals the professionals set were specific and related to their respective disciplines (Wressle et al. 1999a).

4.5.7.2. Goal setting and the patient-therapist relationship

The influence of goal setting on the patient therapist-relationship was discussed in two studies (n=30 participants with stroke, 15 carers and 6 HCPs) (Lawler et al. 1999, Mew and Fossey 1996), one of which had a higher risk of bias than the other (Table 4.2). The nurses in the study by Lawler et al. (1999) perceived a risk of interfering with the positive relationship developed with the patient by imposing goals on them. The nurses also expressed the presence of a tension between establishing a supportive relationship and motivating patients, and the reality of achievable goals (Almborg et al, 2008). Further, the nurses felt that that the term 'goals' could have negative connotations for some people (Almborg et al, 2008). In the study by Mew and Fossey (1996), a negative impact on the patient-therapist relationship resulted due to inconsistencies in the collaborative approach with the patient and an inability to clearly explain the link between the therapist's and the patient's goals. These studies highlighted that collaboration between therapist and patient in the goal setting process is essential for goal setting to have a positive influence on the patient-therapist relationship.

4.5.7.3. Applicability of goal setting

The application of formal methods of goal setting (COPM and GAS) for stoke rehabilitation was evaluated in four studies (n=34 participants with stroke and 5 HCPs) of varying methodological strengths (Jansa et al. 2004, Reid and Chesson 1998, Hale 2010, Mew and Fossey 1996) (Table 4.1 and Table 4.2). It was discussed that these specific methods helped professionals to identify the differences in their goals compared to those of patients (Reid and Chesson 1998, Mew and Fossey 1996). However, the four studies raised concerns that goal setting could not be applied to all participants due to various barriers which are discussed below.

4.5.8. **Facilitators to goal setting**

Four studies identified motivators to goal setting (Black et al. 2010, Jansa et al. 2004, Hale 2010). Professionals considered goal setting to be a tool that enabled them to achieve patient-centred treatment, since goal setting was seen as providing an opportunity for patient participation in problem identification, goal prioritisation and evaluation of goal attainment (Black et al. 2010, Jansa et al. 2004, Hale 2010). Goal setting was also seen by professionals as increasing patient motivation for therapy and maximising the impact of therapists' time (Leach et al. 2010).

4.5.9. **Barriers to goal setting**

Barriers to goal setting were discussed in six studies (Leach et al. 2010, Wressle et al. 1999a, Folden 1993, Hale 2010, Laver et al. 2010, Mew and Fossey 1996). All these barriers were identified by professionals who were either participants in the study or authors of the respective study. Interestingly, the number of identified barriers was greater than the number of facilitators. To obtain an overview, the barriers are categorised as those relating to the patient, treating team and organisation, as presented in the study by Leach et al. (2010).

4.5.9.1. Patient related barriers

Patients' cognitive and communication impairments were identified as the main barriers to goal setting. The HCPs felt that these difficulties may prevent patients from participating in goal setting and that it would be difficult and time consuming to set goals with them (Leach et al. 2010, Hale 2010). It is noteworthy that, of the 17 studies included in this review, only two had included participants with these difficulties (Brock et al. 2009, Wilson et al. 2002). Brock et al. (2009) mentioned that their speech pathologists made small modifications to questionnaires, including simplifying language and creating large type visual aids to ensure the participation of people with

communication and cognitive difficulties in their study. However, as acknowledged by the authors, the validity and reliability of this modified version was not tested. On the other hand, how the issues were handled to ensure patients' participation in goal setting was not explained the study by Wilson et al. (2002). Nine out of 17 studies stated that people with communication or cognitive disorders had been excluded (Wressle et al. 1999a, Almborg et al. 2009, Folden 1993, McAndrew et al. 1999, Phipps and Richardson 2007, Reid and Chesson 1998, Wressle et al. 2002a, Laver et al. 2010, Mew and Fossey 1996). In one study, 51 of 80 (63.8%) patients were not able to complete the COPM (Jansa et al. 2004), while in another, 66 of 321 (20.5%) patients were excluded (Almborg et al. 2009) due to cognitive or communication problems. These figures highlight that cognitive and communication impairments are major barriers and that further work is needed to determine how best to include these patients in the goal setting process.

The other patient-related barriers of goal setting included: (i) lack of understanding of the rehabilitation process, (ii) lack of knowledge and understanding regarding the consequences of stroke and realistic outcomes, (iii) lack of motivation and reluctance to set goals, (iv) depression, (v) lack of readiness to set goals, and (vi) psychosocial issues (Leach et al. 2010, Wressle et al. 1999a, Jansa et al. 2004, Hale 2010, Laver et al. 2010).

4.5.9.2. Barriers related to the treating team

As for the HCPs' perceptions of barriers to goal setting, the main issue was the increased demands on their time due to the difficulty in encouraging patients to express their own goals, especially in those with cognitive and communication issues. Further barriers included: failure to consistently convey the meaning of therapy goals to patients and explain how they related to the patient's own goals; cultural differences between patient and therapist; inability to address goals that require a different setting; difficulty scheduling goal setting meetings between disciplines; and doubts regarding reliability of

tools used for goal setting (Leach et al. 2010, Folden 1993, Hale 2010, Mew and Fossey 1996).

4.5.9.3. Organisational barriers

Shift working of key workers and other professionals, increased work load, and staffing issues were identified as key organisational barriers (Leach et al. 2010, Hale 2010).

4.6. **Discussion**

This systematic review aimed to synthesise evidence pertaining to the effects and experiences of goal setting in stroke rehabilitation.

4.6.1. **Summary of results**

No firm conclusions could be arrived at regarding the effectiveness of goal setting, as there were no RCTs and the methodological quality of most of the studies was weak to moderate. The average age of participants in these studies was also below that of the general stroke population. Despite the limitations, the observational studies suggested that goal setting appeared to positively influence patients' perceptions of participation and self-care ability and may impact on their performance and goal achievement. Randomised trials with robust methodology are now required to substantiate these suggestions.

Patients were often unclear regarding their role in the goal setting process and did not participate fully, whilst professionals seemed to be more positive about the level of collaboration with their patients in goal setting. There were discrepancies between patients and professionals in terms of how they set goals, the types of goals set and how

they evaluated goal attainment. Moreover, several barriers were identified by professionals in relation to the goal setting process, which outnumbered the facilitators.

4.6.2. **Comparison of results with published literature**

The results of this review are comparable to those of Rosewilliam et al. (2011). This more recent systematic review looked at evidence for goal setting in stroke rehabilitation (Rosewilliam et al. 2011). The review explored the nature, extent, and effects of the application of the concept of patient-centred goal setting. Eighteen qualitative studies, eight quantitative studies, and one mixed methods study were included in that review. Since some of the studies did not provide the actual number of participants, a total number could not be obtained. The authors concluded that patient-centred goal setting is only minimally adopted in goal-setting practice and that its effects have not been evaluated rigorously. The review also identified several barriers to goal setting. Although that review explored goal setting, the major focus was on the concept on patient-centeredness. Moreover, the results were based on some mixed population studies as well, which makes it difficult to be confident in generalising the findings to people with stroke. Further, the methodological quality of the studies was not discussed extensively in that review.

On the other hand, the present review appraised the evidence regarding the effects and experiences of goal setting separately and integrated this evidence, which is a necessary step towards making recommendations for best practice. Moreover, both reviews have included different studies, with only five in common. By including studies with stroke-specific data only, one can be more confident in generalising the findings to stroke rehabilitation. Comparatively, the methodological quality of the studies has been considered in greater detail, which adds to the overall quality of the current review. The results also support the conclusions of Kamioka et al. (2009) and Levack et al. (2006a) in that there appears to be no single method of goal setting in stroke rehabilitation.

The results of the review were compared with the studies that were excluded either because of the unavailability of stroke specific data (Gauggel et al. 2001, Gauggel and Fischer 2001, Gauggel et al. 2002, Gauggel and Billino 2002, Bodiam 1999, Bouwens et al. 2009, Gagnes and Hoppes 2003, Holliday et al. 2007b, Liu et al. 2004, Maitra and Erway 2006, McMillan and Sparkes 1999), or the study being a qualitative design with a mixed population (Chen et al. 2002, Conneeley 2004, Holliday et al. 2007a, Kuipers et al. 2004, McGrath and Adams 1999, Nelson and Payton 1997, Young et al. 2008, Baird et al. 2010, Cott 2004, Payton and Nelson 1996, Van de Weyer et al. 2010). Overall, the comparison showed a number of similar results in relation to the effects (e.g. positive changes in COPM scores, perception of greater involvement) and experiences of (e.g. differences between patients and professionals in goal setting), and barriers to goal setting (e.g. lack of patient involvement). One of the differences noted was regarding the effects of goal setting (i.e. specific hard goals are more effective than broad easy goals) demonstrated in the four studies by Gauggel and colleagues (Gauggel et al. 2001, Gauggel and Fischer 2001, Gauggel et al. 2002, Gauggel and Billino 2002). However the limitations of these studies, as discussed in chapter 2, section 2.7.4.1, that the tasks employed were not a true reflection of activities used in stroke rehabilitation, should be noted. Another difference noted was that cognitive and communication impairment highlighted as a major patient-related barrier to goal setting in this review was not given such emphasis in the excluded studies. This could be due to their mixed population sample, which further strengthens the importance of this review concentrating specifically on participants with stroke and their treating team.

4.6.3. **Methods of goal setting**

Ideally the goal setting methods of each study would have been compared against an ideal, or standard, to demonstrate the strengths, weaknesses and missing elements. Although several researchers have made recommendations regarding features of an

effective goal setting method, a recent consensus meeting on goal setting showed that there is no published goal standard for goal setting (Playford et al. 2009). Furthermore, even when formal methods of goal setting (e.g. GAS) were used, researchers modified the procedures, thereby making comparisons difficult (Brock et al. 2009). Similarly, there appears to be no standard theoretical structural framework for goal setting in rehabilitation and information has been drawn from various theories (Playford et al. 2009, Scobbie et al. 2009). As noted earlier, this may have contributed to the variation in the interpretation of goal setting, and the diversity in the methods of goal setting, which hampered the pooling of results. The lack of a standard theoretical structural framework for goal setting, and a standard method of goal setting, was evident in the studies included in the review and in the findings of this review, as discussed below.

4.6.4. **Patient involvement in goal setting**

Although authors stated that participants with stroke were involved in the goal setting process in some studies, the extent to which they were involved was not explained in sufficient detail anywhere (Black et al. 2010, Brock et al. 2009, Folden 1993, Phipps and Richardson 2007, Schweizer et al. 2008, Wilson et al. 2002, Wressle et al. 2002a). This raises concerns, as it emerged that patients were often unclear regarding their role in goal setting and that participation was often low (Almborg et al. 2009, McAndrew et al. 1999, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996). The latter was also reflected in studies that were not included in the review, highlighting that it is not uncommon (Nelson and Payton 1997, Young et al. 2008, Maitra and Erway 2006, Cott 2004, Baker et al. 2001). Apparently, HCPs' claims that they fully involve patients in goal setting are misperceptions in some cases (Maitra and Erway 2006, Baker et al. 2001, Northen et al. 1995, Neistadt 1995). Increasing patient involvement may facilitate patient-centred practice by moving away from a therapist-led goal setting approach (which is more common), towards a patient focussed or patient-centred goal setting approach (Leach et al. 2010, Playford et al. 2000, Barnard et al. 2010).

4.6.5. **Therapist-patient relationship**

Goal setting can influence a therapist-patient relationship both positively and negatively. Conflict that affects the relationship may arise due to the differences in the goals between patients and therapists (Leach et al. 2010, Wressle et al. 1999a, Reid and Chesson 1998, Laver et al. 2010, Lawler et al. 1999, Mew and Fossey 1996, Glazier et al. 2004), including failure to explain how treatment goals reflect a patient's goal (Mew and Fossey 1996). This brings to the forefront the issue of communication between therapist and patient. Several researchers have emphasised the need to improve communication and collaboration to achieve true patient-focussed goal setting (Leach et al. 2010, Maitra and Erway 2006, Gustafsson and McLaughlin 2009, Parry 2004). On a positive note, recognition of this discrepancy was viewed constructively, in that goal setting might help to clarify and agree treatment goals (Reid and Chesson 1998).

4.6.6. **Barriers to goal setting**

Although goal setting was seen as a tool to enable patient-centred care and provide motivation for the patient, several barriers were identified to this process (Leach et al. 2010, Wressle et al. 1999a, Folden 1993, Jansa et al. 2004, Hale 2010, Mew and Fossey 1996), which outnumbered the motivators. The main barriers were the cognitive and communication difficulties presented by the patients, which was apparent from the number of studies that had excluded patients with these difficulties. However, as approximately a third of people with stroke present with communication and cognitive problems (Engelter et al. 2006, Laska et al. 2001), a method to involve these patients is an urgent priority.

The other barriers identified in this review were also reported frequently in studies that were excluded from this review (Playford et al. 2000, Chen et al. 2002, Conneeley 2004,

Kuipers et al. 2004, Van de Weyer et al. 2010, Nualnetr et al. 2010). Education of both patients and professionals, and improved communication, are considered to be key in overcoming these barriers (Leach et al. 2010, Chen et al. 2002, Young et al. 2008, Laver et al. 2010, Baird et al. 2010, Cott 2004, Van de Weyer et al. 2010, Baker et al. 2001, Sumsion and Smyth 2000). Further, education of patients on the complex nature of the disease and the recovery process could help them in setting appropriate goals (Leach et al. 2010, Laver et al. 2010, Rosewilliam et al. 2011, Cott 2004). Training professionals in goal setting methodology and communication skills, and educating them on possible patients' barriers to goal setting and successful strategies to overcome these, are also recommended (Chen et al. 2002, Rosewilliam et al. 2011, Barnard et al. 2010, Sumsion and Smyth 2000, Elsworth et al. 1999).

4.7. **Strengths of the review**

The main strength of this review is that evidence was systematically gathered from all types of studies, including those with quantitative and qualitative designs. Moreover, the review evaluated both effects and experiences of goal setting. The use of a recommended framework to help in the integration of findings, and the use of validated tools to assess methodological quality of the studies were added strengths of this review. Rigour was increased by the involvement of multiple independent reviewers at each stage. A further strength is the use of only stroke-specific data, which enables the formulation of recommendations specifically applicable to stroke rehabilitation.

4.8. **Limitations of the review**

A limitation of the review is that only studies published in English were included, which may have resulted in the loss of some valuable information. However, translation of non-English papers was beyond the scope of this programme of work. A further limitation is that only a single reviewer was involved in the screening of titles and

selecting abstracts, which may have resulted in papers being missed. However, the reference lists of the included studies were screened to identify any missed papers, and no further papers were found. Moreover, the tools used for quality assessment of studies had their own limitations. Although the EPHPP form was designed for the use of non-randomised studies of various designs, some of the criteria, such as confounders, were not applicable to most of the included studies. Some of the rating criteria were not explicit (e.g. the rating for the blinding criteria) and this could have affected the overall rating of individual studies. Similarly, in the critical review form used for assessing the qualitative studies, a high degree of subjectivity was present when deciding whether or not a criterion had been met. The overall rigour of the study had only a 'yes / no' answer and therefore, it was not possible to differentiate between studies with varying degrees of methodological strengths.

4.9. **Implications for practice**

Based on this review, the three points stated below could be put forth as recommendations for best practice:

(i) Communication needs to be improved for a more collaborative goal setting.
(ii) Education and training of professionals regarding goal setting is essential, especially in relation to methods of involving people with communication and cognitive impairments, and should be considered.
(iii) Educating patients about stroke and goal setting could enhance their participation in goal setting, and therefore should be included as part of goal setting.

4.10. **Implications for research**

This review has highlighted the need for further high quality studies, especially relating to the effectiveness of goal setting. The use of the EPHPP instrument and the McMaster

Critical Review Form has helped to identify the methodological issues that need to be considered in future trials. There does not appear to be one standardised method of goal setting, or consensus on how goal setting should be undertaken, especially with people with cognitive and/or communication problems. Discrepancy also exists between perceptions and actual practice relating to the level of patient involvement in goal setting. Therefore, more research is required to design a patient-focussed goal setting method that could enable even those with cognitive and communication difficulties to be more actively engaged.

4.11. **Conclusion**

A systematic review of 17 studies, involving 614 participants with stroke, 43 professionals and 38 carers, was undertaken to evaluate the evidence for the effectiveness and experiences of goal setting in stroke rehabilitation. Although some evidence indicated positive effects of goal setting on performance and goal attainment, the lack of RCTs and high quality studies did not allow any firm conclusions to be reached for the effectiveness of goal setting. In relation to the experiences, differences between patients and professionals were evident on various aspects of goal setting. Several barriers to goal setting were identified, and this outnumbered the number of motivators. Based on these findings, recommendations have been put forth to improve goal setting practice. This included: improved communication between patients and professionals, professional education and training for professionals regarding goal setting, and education of patients on stroke recovery and goal setting.

The findings from this systematic review have been used in the development of a person-centred goal setting intervention specifically tailored for use in the field of exercise after stroke, and this is presented in the next chapter (chapter 5).

5. STUDY TWO: Design and development of a person-centred goal setting intervention

5.1. Introduction

A person-centred goal setting intervention was developed in study two of this programme of work, and is presented in this chapter. First, the rationale for the development of a goal setting intervention is discussed. This is followed by a detailed explanation of how the intervention was developed and its contents.

5.2. Study rationale

To investigate the role of goal setting in exercise after stroke, a goal setting intervention was required. The minimal literature identified in this field in chapter two suggested that the field is relatively new (refer to section 2.7.3). Moreover, none of these identified studies had discussed the method of goal setting employed in detail (Harrington et al. 2010, Huijbregts et al. 2009, Huijbregts et al. 2008, Ownsworth et al. 2008). Therefore, the precise methods of goal setting could not be obtained from these studies. The systematic review discussed in the previous chapter (chapter 4) highlighted the variability in the goal setting methods used in stroke rehabilitation and supported the conclusions made by Kamioka et al. (2009) that there is no one standardised method of goal setting to be used in stroke rehabilitation. It was also identified that formal methods of goal setting were available, however, the variations in their use reduced the standardisation of these tools. Overall, it appears that there is no well-defined, well-structured, formal method of goal setting that could be translated for use in exercise after stroke, and hence, the need to develop such an intervention became essential.

5.3. **Aims**

The aim of this study was to design a formal, evidence-based, theoretically driven, and structured goal setting intervention to be used in the exercise after stroke setting. The development of the intervention is discussed next.

5.4. **Factors considered in the intervention development**

Various factors were considered in the development of this intervention. Firstly, it was essential that this intervention was in line with the recommendations put forth in the previous chapter for an ideal goal setting method (refer to section 4.9). Secondly, the intervention had to be theoretically driven in order to understand its influence on the outcomes. Thirdly, it was considered beneficial to use one of the available formal goal setting methods to provide a structure to the newly designed intervention. These factors are explained in more detail in the following sub-sections.

5.4.1. **Findings from study one**

The systematic review discussed in chapter 4 brought to the forefront various features that should be a part of an ideal goal setting method, the first being the involvement of the patient in the goal setting process. Good communication between the professionals and patients, and improved collaboration between the two were the other features that were highlighted. Further, several barriers relating to the patient were also identified, one of which was lack of knowledge of goal setting. To overcome the barriers, and improve the involvement of patients in the goal setting process, it was suggested that relevant patient education on goal setting is necessary. As for the professional's perspective, the need for sufficient knowledge and training in goal setting was recognised. Therefore, all these recommendations were taken into consideration in the development of the goal setting intervention for this study, thus ensuring it was evidence-based.

5.4.2. **Theoretical underpinning for the intervention**

In chapter two, section 2.7.5, the theoretical background to goal setting was extensively discussed, along with the researcher's rationale for choosing one particular theory to underpin this programme of work. This selection was further justified by the findings of study one, where no evidence was found to support any one specific theory of goal setting. Therefore, the features of Bandura's SCT were integrated in the goal setting intervention of this study. The factors that influence the key constructs of self-efficacy and self-regulation, such as goal ownership, enabling mastery experiences by setting sub-goals and performance attainment, and providing opportunities for feedback were considered in the development of the goal setting intervention.

5.4.3. **Currently used goal setting tools**

A systematic review by Kamioka et al. (2009) identified tools for goal setting currently used in physical therapy and evaluated their application for use with stroke survivors. The most commonly used goal setting methods included Goal Attainment Scaling (GAS), the goal forum intervention, and the Canadian Occupational Performance Measure (COPM) (Kamioka et al. 2009). Although the authors identified strengths and limitations for all these tools, on comparison, they were in favour of the goal forum intervention and GAS. However, they recommended that these tools need to be developed further to enable effective use in stroke rehabilitation. Among the literature discussed in the background on goal setting in stroke (chapter 2, section 2.7) and in the systematic review on goal setting (chapter 4), GAS and the COPM were the most frequently reported goal setting methods. The goal forum intervention did not feature at all. Therefore, only GAS and the COPM are explored in the following sub-sections and finally, an overall comparison is made to enable the choice of tool for use in this intervention.

5.4.3.1. Goal Attainment Scaling

GAS is one of the tools that allows for the individualisation of the patient's goals according to their needs. The development of the tool, the procedure to use it, its psychometric properties, and the strengths and limitations are discussed below.

5.4.3.1.1. Development of Goal Attainment Scaling

Kiresuk and Sherman (1968) identified a need to develop a standardised tool that not only evaluated their mental health programme, but could also formally specify the actual goals that had been addressed by the staff to aid in program evaluation. Accordingly, they developed GAS (Kiresuk and Sherman 1968).

Although developed for mental health settings, the individualised nature of GAS allowed professionals to use the tool in various other settings, such as social work, psychiatric hospitals, nursing homes, and rehabilitation centres, and in other programs such as family therapy, special education, and substance-abuse treatment (Gauggel and Hoop 2004, Malec 1999, Goodyear and Bitter 1974). Within rehabilitation, GAS has been used with diverse populations, such as brain injury, stroke, multiple sclerosis, chronic pain and amputations (Malec 1999, Turner-Stokes 2009).

5.4.3.1.2. Procedure of Goal Attainment Scaling

The procedure for using GAS has been extensively described by several authors (Kiresuk and Sherman 1968, Malec 1999, Turner-Stokes 2009, Joyce et al. 1994, Stolee et al. 1992). The process of GAS involves six steps, as described in Table 5.1. It should be noted that the involvement of the patient within each of these steps has not been made clear.

Table 5.1: Goal Attainment Scaling procedure

(Kiresuk and Sherman 1968, Malec 1999, Stolee et al. 1992)

Step 1: Goal selection

- Identification of goals with the patient after assessment.
- Goals developed into goal statements for clarity.
- No restrictions on the number of goals, however, three to six specific goals are recommended (Malec 1999).

Step 2: Weighting goals

- Each goal given a weight according to the importance of the selected goal.
- Weighting could be 1, 2, 3, or 10, 20, 30 or even 2, 4, 6 and not essential.
- If all goals are equally important, a weighting of 1 could be given to all the goals.

Step 3: Designation of follow-up time period

- Follow-up period decided to assess goal attainment.
- Time period could be the end of intervention or an interim period, based on the programme in evaluation.

Step 4: Articulation of the 'expected' level of outcome

- The goal set and time period for follow-up are articulated in an objective way.
- This 'expected' level of outcome is represented by a numeric value of 0.
- This should demonstrate a goal achievement that is realistic in nature to both the patient and the professional.

Step 5: Articulation of other outcome levels

- The other scale levels are completed in an objective way.
    - +2 → much better than expected
    - +1 → somewhat better than expected
    - -1 → somewhat less than expected
    - -2 → much less than expected
- Levels set for all the selected goals and documented.

Step 6: Assessment of GAS scores

- The current GAS levels and levels at follow-up are documented for all goals.
- GAS scores calculated using the formula below:

$$\text{Overall GAS 'T'} = 50 + \frac{10\,\Sigma(w_i\,x_i)}{[(1-\rho)\,\Sigma w_i^2 + \rho(\,\Sigma(w_i)^2]^{1/2}}$$

where, X_i = the attainment level; W_i= the weight assigned to the goal;

ρ = weighted average of intercorrelation of the scales score, usually set as 0.30.

- A 'T' score of 50 demonstrates that the person has achieved the 'expected' level of outcome.

5.4.3.1.3. Psychometric properties

The psychometric properties of GAS have been evaluated in different settings including stroke and brain injury (Malec 1999, Turner-Stokes et al. 2009, Kamioka et al. 2009, Turner-Stokes 2011). A systematic review by Kamioka et al. (2009) reviewed tools of goal setting and included 17 studies that had evaluated the psychometric properties of GAS, of which three studies were with stroke participants. Among these three studies, one study looked only at the clinical utility of GAS (Reid and Chesson 1998), while the other two studies included participants with stroke as part of the frail elderly population (Stolee et al. 1992, Stolee et al. 1999). Although validity and reliability were not investigated specifically in patients with stroke, based on the results of studies with brain injury patients and frail elderly patients, the authors concluded that GAS could be a useful tool for use in people with stroke. However, they put forth recommendations that all the psychometric properties of GAS need to be evaluated in participants with stroke.

Another systematic review by Hurn et al. (2006) reviewed goal setting as an outcome measure and included 15 studies. Based on 11 studies that focussed on the psychometric

properties of GAS, the authors concluded that GAS could be a valid and reliable tool for use in neurological rehabilitation (Hurn et al. 2006). However, as in the review of Kamioka et al. (2009), the results were based on studies with brain injury patients and only a small number of participants with stroke. The types of goals set and the time-frames involved may be different between brain injury and stroke patients, and therefore, these results need to be interpreted with caution for use in stroke rehabilitation.

5.4.3.1.4. Strengths and limitations

As with all tools, GAS has its own advantages and disadvantages. Ertzgaard et al. (2011) discussed these in detail in their recent paper on GAS. The utility and feasibility of using GAS demonstrated in various studies serve as a great strength of GAS (Turner-Stokes 2009, Turner-Stokes et al. 2009, Reid and Chesson 1998, Turner-Stokes and Williams 2010, Turner-Stokes et al. 2010). However, the involvement of the same research groups in the evaluation of GAS should not be overlooked. Another strength of the tool is that it can be used as a method of goal setting and as an outcome measure as well.

However, the limitations of the tool appear to outnumber the strengths. As pointed out by Donnelly and Carswell (2002), GAS was designed as an individualised tool and not necessarily as a client-centred measurement. As per the original protocol, the goal setting is done by independent assessors and the involvement of the patient is not specified (Cytrynbaum et al. 1979). Therefore, the whole notion of using GAS as a tool for patient-centred goal setting could be questioned. Moreover, the procedure of GAS is being modified by different users, which again raises questions about the validity of the tool (Malec 1999, Turner-Stokes 2009, Brock et al. 2009, Hale 2010, Bovend'Eerdt et al. 2011). The changes were apparent in the procedure of weighting the goals, setting the levels of ‘expected outcome’ and the scoring methods (Brock et al. 2009, Turner-Stokes 2011, Bovend'Eerdt et al. 2011).

Further, the reliability between professionals in setting the indicators, difficulty in using the tool in people with cognitive problems, and time consumption have also been identified as limitations of the tool (Hale 2010). Finally, the involvement of a complex mathematical formula in the calculation of goal attainment scores has been highlighted as a major limitation by the professionals using GAS (Tennant 2007, Hale 2010). What the conversion of patients' personal goals into complex numbers would mean to the patients is also unclear. The debate on its merits versus demerits continues to date (Turner-Stokes et al. 2009, Brock et al. 2009, Turner-Stokes 2011, Bovend'Eerdt et al. 2011).

5.4.3.2. The Canadian Occupational Performance Measure

The COPM is a patient-centred outcome measure which can also be used as a tool to set goals. Law et al. (2005, p.1) defines COPM as: "an individualised measure designed for use by occupational therapists to detect changes in a client's self-perception of occupational performance over time".

The development of the tool, the procedure for using it, its psychometric properties, and the strengths and limitations are discussed in the following sections.

5.4.3.2.1. Development of the Canadian Occupational Performance Measure

When Occupational Therapy (OT) guidelines for client-centred practice were developed in the 1980's, it was recommended that a tool be developed for use specifically for OT (Law et al. 2005). Further, several criteria that should be met by this outcome measure were also identified. However, no outcome measure satisfied all the criteria and therefore, it was decided to develop a new tool. After several review processes in the late 1980's, the tool was developed in the early 1990's and first published in 1991 (Law et al. 2005). This tool was called the COPM and was developed by the Canadian Association of Occupational Therapists.

The COPM is based on the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists 2002). This model emphasises the involvement of the patient in the therapeutic process and also recognises the individuality of each patient (Canadian Association of Occupational Therapists 2002). The model includes beliefs that the patients are experts regarding their needs and therefore, the omission of their perspective in their care will not yield expected outcomes (Canadian Association of Occupational Therapists 2002). Thus, the COPM was developed based on the concept of client-centredness. The CMOP states that "occupational performance is an experienced phenomenon rather than an observed phenomenon" (Law et al. 2005, p.5). It further adds that occupational performance incorporates both performance and satisfaction and is influenced by roles and environment (Law et al. 2005, Canadian Association of Occupational Therapists 2002). Thus, the developers have tried to incorporate all the elements of the CMOP into the design of the COPM.

Although the COPM was originally designed for use by Occupational Therapists, it is now being widely used by all members of the multi-disciplinary team (Law et al. 2005). The COPM is also being employed in a variety of disorders, such as stroke, cerebral palsy, spinal cord injury, arthritis, pulmonary diseases, mental ill-health, and haemophilia and in both hospital and community settings (Kamioka et al. 2009, Law et al. 2005, Carswell et al. 2004, Jenkinson et al. 2007). Law et al. (2005) further add that the COPM has been used in around 35 countries and has been translated into more than 20 languages, demonstrating its wide use.

5.4.3.2.2. Procedure of the Canadian Occupational Performance Measure

The COPM is administered as a semi-structured interview. Although the manual suggests it should take only 15 to 30 minutes to administer the COPM, other researchers using the COPM have suggested an administration time of 30 to 45 minutes (Jansa et al.

2004, Phipps and Richardson 2007). The procedure to use the COPM involves the following four steps (Law et al. 2005):

Step 1: Problem identification

The assessor interviews the patient about his/her occupational performance. The patient is encouraged to identify occupations that are not only the current main problems, but problems that are also relevant to their roles in daily life. To help both the patient and the assessor, the data collection form is divided into three areas, including self-care, leisure and productivity. These areas are further sub-divided, with some activities mentioned to act as guides. The data collection form can be found in Appendix 6.

Step 2: Rating importance

Once the specific problems have been identified, the patient is asked to rate each of the problems in order of its importance in his or her life. Importance is rated on a scale of 1-10, where 1 is 'not important at all' and 10 is 'extremely important'. This step is to ensure that patients' priorities are considered in the treatment plan, thereby facilitating patient-centred intervention. The patient is then asked to choose three to five problems that are the most important to them.

Step 3: Scoring

The patient is asked to rate his/her current performance of each chosen problem/activity on a ten point scale, where 1 is 'not able to do it all', and 10 is 'able to do it extremely well'. The patient is then asked to rate his/her satisfaction with the current performance of each chosen problem/activity on a ten point scale, where 1 is 'not able to do it all', and 10 is 'able to do it extremely well'. The performance scores are added up and then divided by the number of identified problems to generate an average performance score which is in the range of 1 to 10. In a similar manner, the average satisfaction score is also calculated.

Step 4: Reassessment

During reassessment, for the same selected problems, step 3 is repeated to generate an average performance and satisfaction score. The changes in performance and satisfaction are calculated by subtracting time 1 values from time 2 values.

5.4.3.2.3. Psychometric properties

A systematic review by Kamioka et al. (2009) on goal setting tools included 13 studies that had evaluated the psychometric properties of the COPM, of which only one study had included participants with stroke. The authors concluded that although the COPM may be useful in determining the subjective goal attainment of patients, the tool lacked objectivity (Kamioka et al. 2009). However, this criticism of the tool could be questioned because the subjectiveness of the COPM is actually embedded within the tool, as it was developed with the core assumption that occupational therapy is based on the experiences of the person (Law et al. 2005). Another literature review which concentrated only on the COPM identified 88 studies, including six with stroke participants (Carswell et al. 2004). The COPM had been used for various reasons in these studies, of which 19 studies were on psychometric properties (Carswell et al. 2004). Although the authors recognised the subjective nature of the tool, they agreed that the tool was designed to capture the patient's perceived needs and goals, and that it was intended to be subjective and not norm-referenced. Therefore, based on the results of the studies they had included, they concluded that the COPM was a valid, reliable, clinically useful and responsive outcome measure. A third literature review evaluated six individualised client-centred outcome measures including the COPM (Donnelly and Carswell 2002). The reviewers recognised the strong theoretical background of the COPM. However, it should be recognised that all these reviews had included papers with participants of various disabilities and not stroke alone and therefore, results need to be interpreted with caution for use in stroke rehabilitation.

In studies with stroke survivors, the COPM scores and change scores have been compared with a wide range of outcome measures such as Barthel Index, EuroQOL, Frenchay Activities Index, the Disability and Impact Profile, Sickness Impact Profile 68, the Reintegration to Normal Living Index, the Life Satisfaction questionnaire, and the Impact on Participation and Autonomy (Chen et al. 2002, Cup et al. 2003, Dedding et al. 2004, McColl et al. 2000). These comparisons were conducted to determine the different types of validity for the COPM, namely, discriminant validity, criterion validity, convergent, and content validity. Taken together, the results of the studies supported the various aspects of validity of the COPM. The uniqueness and the usefulness of the COPM were established, with the COPM helping to identify more patients' problems than other measures (Jenkinson et al. 2007, McColl et al. 2000, Toomey et al. 1995).

The inter-rater reliability of the COPM, and reproducibility of the mean performance and satisfaction scores were moderate in two studies with stroke participants (Cup et al. 2003, Eyssen et al. 2011). Authors of two different studies concluded that the COPM was a responsive measure in detecting change of performance and satisfaction of stroke survivors (Eyssen et al. 2011, Wressle et al. 1999b).

5.4.3.2.4. Strengths and limitations

The main strength of the measure is that it is a patient-centred outcome measure and concentrates on the individual's own perception of their problems and their priorities. Moreover, it can be used as a tool to set goals as well (Law et al. 2005). Further, the COPM provides an opportunity for the participant to be involved in his/her own treatment and may improve the patient-professional interaction (Wressle et al. 2002a, Wressle et al. 2002b). The COPM not only concentrates on the self-report of performance of an activity, but also on satisfaction, which may be important to the patient (Law et al. 2005). Since COPM reassessment scores are compared to the individual's previous scores, the changes may be more relevant and meaningful than comparison with a norm (Wressle et al. 2002b).

However, some of the strengths of the measure serve as limitations too. The individualised nature of the measure rules out the possibility of a norm and therefore, comparisons of group changes using the measure have been questioned. As mentioned earlier, further questions were also raised regarding the subjective nature of the tool and the lack of objectivity (Kamioka et al. 2009). Goals identified by COPM have been reported to change over time and hence reassessment is essential at regular intervals (Cup et al. 2003). The long administration time and the interviewing skill required by the assessor to elicit responses from the patients were also seen as limitations of COPM (Wressle et al. 2002b, Chan 1997). It has been pointed out that patients tend to get confused with the terminologies and the scoring methods (Eyssen et al. 2011, Chan 1997). However, Eyssen et al (2011) reported that the difficulties in scoring experienced by patients reduced significantly during reassessment. Another major limitation of COPM was the use of the tool in patients who lacked insight, and in those with communication and cognitive impairments (Jansa et al. 2004, Chan 1997). In a study by Jansa et al. (2004), only 36% (26 of 80) of the total sample was able to complete the COPM for the above reason, which is low. Lastly, the individualised nature of the tool suggests that the COPM should not replace other standardised outcome measures, but should be used in conjunction with other measures.

5.4.3.3. Goal setting tool selection

On detailed exploration of the two tools of goal setting, namely, GAS and the COPM, it was decided that the COPM would be used as part of the goal setting intervention for this study. As pointed out earlier (section 5.4.3.1.4), the limitations of GAS outnumbered the strengths. GAS and its scoring depend more on the assessor and therefore, the extent of involvement of the patient could be questioned. Both GAS and the COPM could be criticised for their subjectivity, however, the subjectivity of the COPM depends on the patient, while the subjectiveness of GAS comes additionally from the assessor as well. With the focus of this programme of work being on person-centred goal setting, subjectivity of the patient is expected and the COPM fits with this

expectation. Also, the COPM was developed with the concept of client-centeredness in mind and is consistent with the concepts within Bandura's Social Cognitive Theory that was selected for this programme of work. The patient has the central role in both the COPM and the SCT, which is pivotal within this programme of work. GAS, on the other hand, could not be fitted within this person-centred framework, as the involvement of the patient appeared to be minimal.

Overall, on comparison with GAS, strengths of the COPM outweighed the limitations. Moreover, the COPM relates more closely to the concept of patient-centeredness than GAS. Hence, it was decided that the COPM would be used as part of the goal setting intervention in this study.

In summary, three sources, namely findings from the systematic review (study one), the theoretical underpinning, and the currently used goal setting tools were considered in the development of the person-centred goal setting intervention to be used with exercise after stroke in this programme of work. How these sources were integrated into the intervention is presented next.

5.4.4. **Integrating sources within the intervention design**

As explained above, three sources were considered for the development of the intervention. What the sources contributed and how they were integrated within the actual design of the intervention are presented in Figure 5.1.

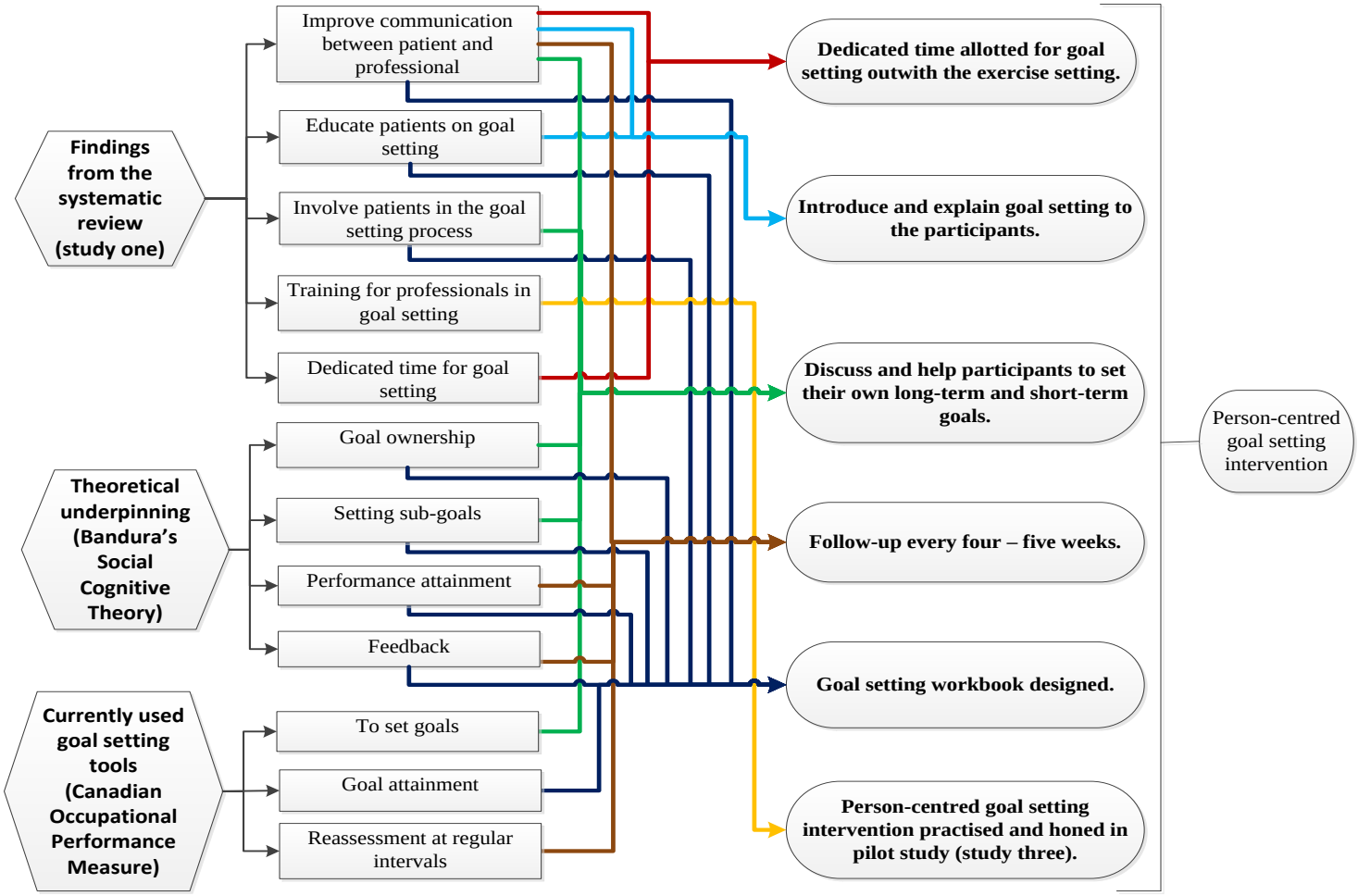

Figure 5.1: Integrating different sources of information to design the person-centred goal setting intervention

5.5. **Components of the goal setting intervention**

The six main components of the goal setting intervention, as seen on the right hand side of Figure 5.1, are explained in detail in the following sub-sections. The goal setting intervention was designed for stroke survivors, and they are referred to as participants hereafter in this chapter.

5.5.1. **Time for goal setting**

Evidence gathered from the literature recognised lack of time as one of the major barriers to goal setting (Leach et al. 2010). The time taken to set goals was also considered a barrier to the implementation of goal setting (Leach et al. 2010, Hale 2010). Therefore, it was decided that goal setting would be done outwith the exercise setting in a formal manner, but without time limitations. It was believed that this separate time allotted for goal setting would ensure that participants were not rushed when asked to think about their problems and decide on goals. This dedicated time would also allow sufficient time to answer questions raised by the participants, thereby allowing for improved communication, which was one of the recommendations made in study one.

5.5.2. **Introduction to goal setting**

Based on the evidence from studies on goal setting in stroke rehabilitation, the systematic review presented in chapter 4 recommended that educating stroke survivors on goal setting is essential, and that this may increase their involvement in the goal setting process. Accordingly, it was planned that participants receiving this intervention would be educated on goal setting first, before beginning the process of goal setting. Education on goal setting would include an interactive discussion of the following: the term ‘goal setting’, roles of the participant and the researcher in goal setting, how goal setting was expected to work, and how goal setting would be done. It was believed that this education and detailed introduction would break down any barriers in

communication between the participants and the researcher to ensure effective collaboration.

5.5.3. **Participant involvement in goal setting**

Several researchers have advocated for the involvement of patients in the goal setting process (McGrath and Davis 1992, Wade 2009, McClain 2005, Barnard et al. 2010). Studies in which participants were involved in the goal setting process have demonstrated better treatment outcomes than those participants who were not involved in the process (Annesi 2002, Wressle et al. 2002a, Webb and Glueckauf 1994, Duncan and Pozehl 2003, Schultz 1993, Stenstrom 1994, Theodorakis et al. 1997). Although some of these studies included participants with health conditions other than stroke, and some studies had various methodological limitations, patient involvement in goal setting appeared to be beneficial. The systematic review presented in chapter 4 identified that there was a lack of information in most studies as to whether patients were involved in goal setting (and if so, how), and recommended that patients should be involved to maximise benefits from the treatment.

As discussed in section 2.7.5.1, Bandura's SCT emphasises that personal goals and goal setting serve as motivators for better performance (Bandura 2005, Bandura 1986, Bandura 1997). This theory also recognises the role of the individual's self-efficacy and self-regulatory skills involved in goal setting and goal attainment (Bandura 2005, Bandura 1986, Bandura 1997). All these points lead to the theoretical rationale that participants need to be involved in the goal setting process and have ownership of the goals, for goal setting to have the desired effects. Another important concept proposed in this theory is the importance of creating short-term (proximal) and long-term (distal) goals (Bandura 2005, Bandura 1986, Bandura 1997).

Based on the findings from the literature and theoretical knowledge, it was decided that participant involvement in goal setting should be maximised, and that they should have

ownership of their goals. Therefore, a detailed discussion with the participants on the identification of problems and setting of goals was the core component of this goal setting intervention. It was decided that at every stage, participants would be encouraged to take part in the process, and their role in this process and its importance would be stressed at all times by the researcher. The participant's active role in this process would be emphasised by explaining that it was the participant's goals that were being discussed and not the researcher's, and that the researcher's role was only to help the participant identify and set goals. The COPM would be used to aid the setting of goals. It was believed that identifying the importance, performance, and satisfaction of each goal through the COPM would help the participant to think about and prioritise their goals.

Based on the selected theory, the decision was that each long-term goal would be broken down into several short-term goals through discussion with the participants. The researcher would explain to the participants the need for this step, and how the short-term goals would lead up to the long-term goal. As discussed in the above paragraph, participant involvement would be encouraged and maximised at this stage.

5.5.4. **Goal setting follow-up**

Bandura (2005, 1986, 1997) highlights the importance of feedback to improve self-efficacy, and thereby motivation and performance. Literature on goal setting has identified that goals change over time, requiring regular follow-up. Similarly, researchers using the COPM have also stressed that regular reassessment is necessary as goals may change (Cup et al. 2003). Regular follow-up may also prevent any breakdown in communication between the participants and the researcher.

Therefore, for the goal setting intervention in this study, it was decided that regular follow-ups would be conducted. It was believed that these follow-ups would provide an opportunity for the participant to reflect on their progress on goals, set new goals if desired, modify the previously set goals, and also discuss any barriers faced. The COPM

would be used at this stage to provide feedback to the participants on goal attainment. In order for the participants to work on their goals and reflect on their progress, it was necessary not to conduct the follow-up assessment too soon. On the other hand, reassessing after too lengthy an interval might lead to a participant not having a chance to discuss their goal progress and goal changes. On discussion with the team, a time period of four to five weeks for follow-up was considered appropriate, and hence it was agreed that goal setting follow-up assessment would be conducted every four to five weeks.

5.5.5. **Goal setting workbook**

As goal setting was considered a motivational tool to improve physical activity performance, it was deemed necessary to maximise participant involvement to help develop a sense of ownership. In line with this, a goal setting workbook for home use was designed. It was expected that the workbook would serve as a reminder for the participants of the goals set and also help them record their progress. Concepts from the findings of study one (i.e. patient involvement in goal setting), the chosen theory (i.e. goal ownership, setting sub-goals, performance attainment and feedback), and the COPM (i.e. goal attainment) were all used to develop the contents of the workbook (Figure 5.1). It was believed that the workbook would also serve as a communication tool between the participants and the researcher.

The meaning of goal setting, the participant's role in this, how goal setting was expected to work, and how to complete the workbook were all outlined at the beginning of the workbook to remind the participants of this information. Following this, pages to document long-term goals, monthly goals and weekly goals were provided. For every week, the participants could mark their goal attainment on a scale of 0 to 100, where 0 indicated 'no goal attainment' and 100 indicated 'achieved all the goals'. The participants also had questions to complete every week regarding barriers and motivators. Each workbook covered one month, and it was planned that a new workbook

would be provided for every month. It was planned that at the start of the intervention, the researcher would explain to the participants how the short-term goals would lead up to the long-term goals, and also would help them to set their weekly goals. During follow-up visits, the participants would be encouraged to set their own weekly goals, as part of self-management and ownership of goals and their condition. A copy of the goal setting workbook is attached as Appendix 7.

5.5.6. **Training in goal setting**

Lack of expertise regarding effective goal setting was one of the commonly cited barriers that related to professionals (Leach et al. 2010). The systematic review presented in chapter 4 recommended that professionals should be educated and trained in goal setting. Therefore, the following measures were taken to ensure that the researcher delivering the goal setting intervention was trained in goal setting before the start of the study:

(i) Background reading on goal setting literature
(ii) Knowledge of theories of goal setting
(iii) Discussions with persons who were experienced in undertaking goal setting
(iv) Reading on the COPM
(v) Discussions with persons who had used the COPM

Once the researcher had developed the necessary skills, the person-centred goal setting intervention was practised and honed in a pilot study, presented as chapter 6.

5.6. **Goal setting procedure**

Participants in the next two studies (study three – chapter 6, study four – chapter 7) received the person-centred goal setting intervention developed in the current study. The intervention procedure is described in this section.

The participant's current understanding of goal setting was sought first. The researcher then explained the meaning of goal setting to the participants (i.e. goal setting is a process by which goals that are important to them will be identified and set), and how goal setting was expected to work. The meaning of a goal was also explained by providing an example of a goal, such as 'to be able to walk to the shop located around 500 metres from the house in six weeks' time'. The active role of the participants in this process was emphasised by explaining that it would be their goals that were discussed and not the researcher's, and that the researcher's role was only to help them to identify and set goals.

As a next step, the context of the study (i.e. goal setting in exercise after stroke) was discussed with the participants. This was done to ensure that goals relevant to exercise after stroke were being set and monitored, and also to avoid discussions about goals that were beyond the remit of the study (e.g. improving communication, or cognitive issues). Any questions of the participants were answered at this stage. To help the participants identify and prioritise their goals, the structure and content of the exercise classes were then outlined. The participants were asked if they had any goals set for the exercise classes. Their expectations and reasons for joining the exercise classes were also discussed.

The participants were then asked to list their problems since stroke. If participants found it difficult to do this, they were asked to describe activities in a typical day before stroke and after stroke. It was believed that this procedure would help participants to identify problems, and also improve collaboration between the participant and researcher. The problems listed by the participants were then discussed in detail. This provided an opportunity to identify whether the problems were related to physical activity, e.g. if the participant identified shopping as one of the problems, detailed discussion helped in identifying which component of shopping was an issue. If the problem was with the walking component of the shopping, then it was considered for the study. On the other

hand, if the problem was related to the money handling component of shopping, then it was explained to the participant that the particular problem was beyond the remit of the current study, and they were asked to contact their General Practitioner (GP) for referral to a relevant professional.

After discussion, all problems relating to physical activity were listed. The participants were again reminded that the study was in the context of exercise after stroke and therefore, only problems related to physical activity would be considered. However, they were encouraged to talk to their GP about their other problems. With the COPM rating scales, the participants were then asked to rate the importance of each of their selected problems on a scale of 1 to 10, where 1 indicated 'not important at all' and 10 indicated 'extremely important'. Up to the top five most important problems were then identified and chosen, for which the performance scores and satisfaction scores were obtained using the COPM rating scales.

Each of the problems was formulated into a goal by the researcher, upon discussion with the participant. On further discussion with the participant, each goal was articulated with a specific and realistic time-frame. During all these discussions, the participants had more input than the researcher. The researcher only aided the participants to be realistic and specific, and clearly explained why the participants needed to re-think, if required. This procedure was followed to allow the participants to take ownership of their goals and their recovery. The participants were then given time to think of the goals discussed, and asked if they had missed out any other problems, and these were also taken into consideration.

Once the goals were finalised, the goal setting workbook was introduced. The purpose of the workbook and the expected contribution from participants were also outlined. The researcher then took the participant through the workbook and explained how the long-term goals could be achieved by breaking them down into short-term goals (both

monthly and weekly goals). The sections where the participants could score their goal progress and add their comments on barriers and motivators were also pointed out. The long-term goals discussed were documented in the workbook. On discussion with the participant, the monthly goals for the first month were then decided and documented. The participants were encouraged to complete the weekly goals. If requested, the researcher helped in setting the weekly goals. The participants were informed that the goals would be reviewed every four to five weeks.

During follow-up visits, performance and satisfaction scores for the previously identified problems were obtained using the COPM rating scales. Once the participants provided their current performance and satisfaction scores, they were shown their previous ratings, and any changes noted were discussed. Providing participants with this knowledge of performance was in line with the chosen theory (refer to section 2.7.5.1). The goals documented in the workbook were then discussed in detail with the participants, and their plans for the next time period were discussed. Accordingly, the goals were modified, or new goals added for the next month. Within these discussions, the barriers and motivators identified in the workbook were also addressed. Suggestions for overcoming the barriers were provided by the researcher.

At all stages, the benefits of physical activity and the importance of physical fitness after stroke were emphasised to the participants, to encourage them to work towards their goals.

5.7. **Conclusion**

This chapter discussed the development of a person-centred goal setting intervention for use in exercise after stroke, with emphasis on theory, evidence and formal structure. Accordingly, the constructs of the SCT, the findings from the systematic review conducted as study one of this work, and the COPM were used to develop this intervention. The individual components of this intervention, namely time for goal

setting, introduction to goal setting, participant involvement in goal setting, goal setting follow-up, goal setting workbook, and training in goal setting were identified and defined. The intervention procedure was then described. This intervention was refined and familiarised within study three of this programme of work, presented in the next chapter (chapter 6). The feasibility of this intervention is then addressed in study four (chapter 7).

6. STUDY THREE: Pilot testing the goal setting intervention and validation of the activPAL™ activity monitor

6.1. Introduction

According to the MRC framework for complex interventions, a newly designed intervention should be pilot tested to identify and modify uncertainties in the design and content of the intervention (Craig et al. 2008). Additionally, it is recommended that the outcome measures should be finalised and validated if necessary (Craig et al. 2008). Accordingly, a pilot study with multiple aims was conducted, and is presented in this chapter. First the rationale for the validation of the activPAL™ is briefly explained, followed by the aims, methods and results of the current study. The findings are discussed next with conclusions at the end of the chapter.

6.2. Rationale for the validation of the activPAL™ activity monitor

The literature reviewed in chapter 2, section 2.9.1 highlighted the limited evidence for the psychometric properties of the activPAL™ monitor in the stroke population. Moreover, the identified stroke-related literature had limitations, such as mixed populations (Taraldsen et al. 2011), and exploration of only one specific variable (Harris et al. 2006). Further, it was believed that parameters such as gait pattern, and speed of walking may differ between a healthy older adult and a stroke survivor (e.g. reduced heel strike and/or toe-off, slow walking speeds). These parameters may affect the acceleration signals recorded and processed by the activity monitor, and therefore, extrapolating results from another population to stroke may not be valid. Therefore, it was decided that a study would be conducted to evaluate the validity and reliability of

the activPAL™ activity monitor on all its measurement variables for use with people who have had a stroke. In line with the previous studies (Grant et al. 2008, Grant et al. 2006, Ryan et al. 2006), it was decided that video observation would be used as the criterion measure in the current study.

6.3. **Aims**

The aims of the study were to:

(i) Pilot test the person-centred goal setting intervention developed in study two (chapter 5). This included: honing the skills of the researcher in delivering this intervention, identifying any difficulties in the initial application of the intervention, and obtaining feedback from the participants on the goal setting workbook.

(ii) Gain familiarity with the use of the other outcome measures (10MWT, TUG test, SIS, SSEQ) to ensure fidelity, where fidelity was defined as "the degree of exactness with which something is copied or reproduced" (Oxford University Press 2013).

(iii) Validate the activPAL™ activity monitor for use in people with stroke. This aim was deconstructed further into the following objectives:

  (a) Evaluate the concurrent validity of the activPAL™ activity monitor for use with people with stroke against video observation as the criterion measure.

  Validity is defined as "the extent to which an instrument measures what it is intended to measure" (Sim and Wright 2000, p.32). Sim and Wright (2000, p.126) state that "concurrent validity is established by comparing the performance of a measuring instrument against an independent standard, in respect of the same entity at the same time".

  (b) Demonstrate the intra-observer reliability of the video observation to justify its use as the criterion measure for the above aim.

(c) Demonstrate the inter-device reliability of the activPAL™ activity monitor for use with people with stroke.

Reliability is defined as "the extent of reproducibility or consistency of values measured under specified conditions" (Sim and Wright 2000, p.32). Inter-device reliability refers to the degree to which two similar instruments (two activPAL™ monitors in this case) yield similar results at the same time (Medical Research Council 2013). Establishing this property would allow for comparisons between the activity monitors.

(d) Establish the test-retest reliability of the activPAL™ activity monitor for use with people with stroke.

The test-retest reliability is defined as "the degree to which a result with one instrument is equivalent to the result on the same or a parallel instrument across days" (Medical Research Council 2013). Establishing this property would allow for comparisons of findings over several data collection points.

6.4. **Methods**

6.4.1. **Study design**

A cohort study with a repeated measures design was employed for this study.

6.4.2. **Ethical approval**

The study and subsequent amendments were approved by the South East Scotland Research Ethics Committee 03 and by the Research and Development Department of NHS Lothian (Appendix 8).

6.4.4. **Study population**

Participants who were participating in the selected Exercise after Stroke service (EaS) were recruited for the study in the early stages of the recruitment process (refer to section 2.5 for details of the service). Initially, the Sports and Development officer of the EaS service agreed to contact clients participating in the EaS classes to obtain permission for the researcher to contact them regarding the study. If they agreed, the contact details of clients were passed to the researcher, who then contacted them with the information sheet and confirmed their participation in the study. Due to staff workload changes, the role of first point of contact was passed onto the Exercise Instructor who was in charge of the EaS classes.

Recruitment to the study began in June 2011. However, due to low recruitment to the EaS classes, staff and management changes, and increased workload of the staff involved, only five participants (of the ten that were contacted by the researcher) were recruited by February 2012. The aim was to recruit 15 participants. This warranted an additional recruitment strategy.

Therefore, it was decided that participants would be recruited from a hospital setting in the same city. A Research Nurse introduced the study to potential participants and obtained permission to pass on their details to the researcher. The researcher then contacted the participant with the detailed information sheet and confirmed participation.

Recruitment to the study continued until the end of January 2013. A signed informed consent form was obtained from the participants once they agreed to participate. The information sheet that was provided to the participants and the consent form are attached as Appendix 9. A flowchart of the study procedure is presented as Figure 6.1.

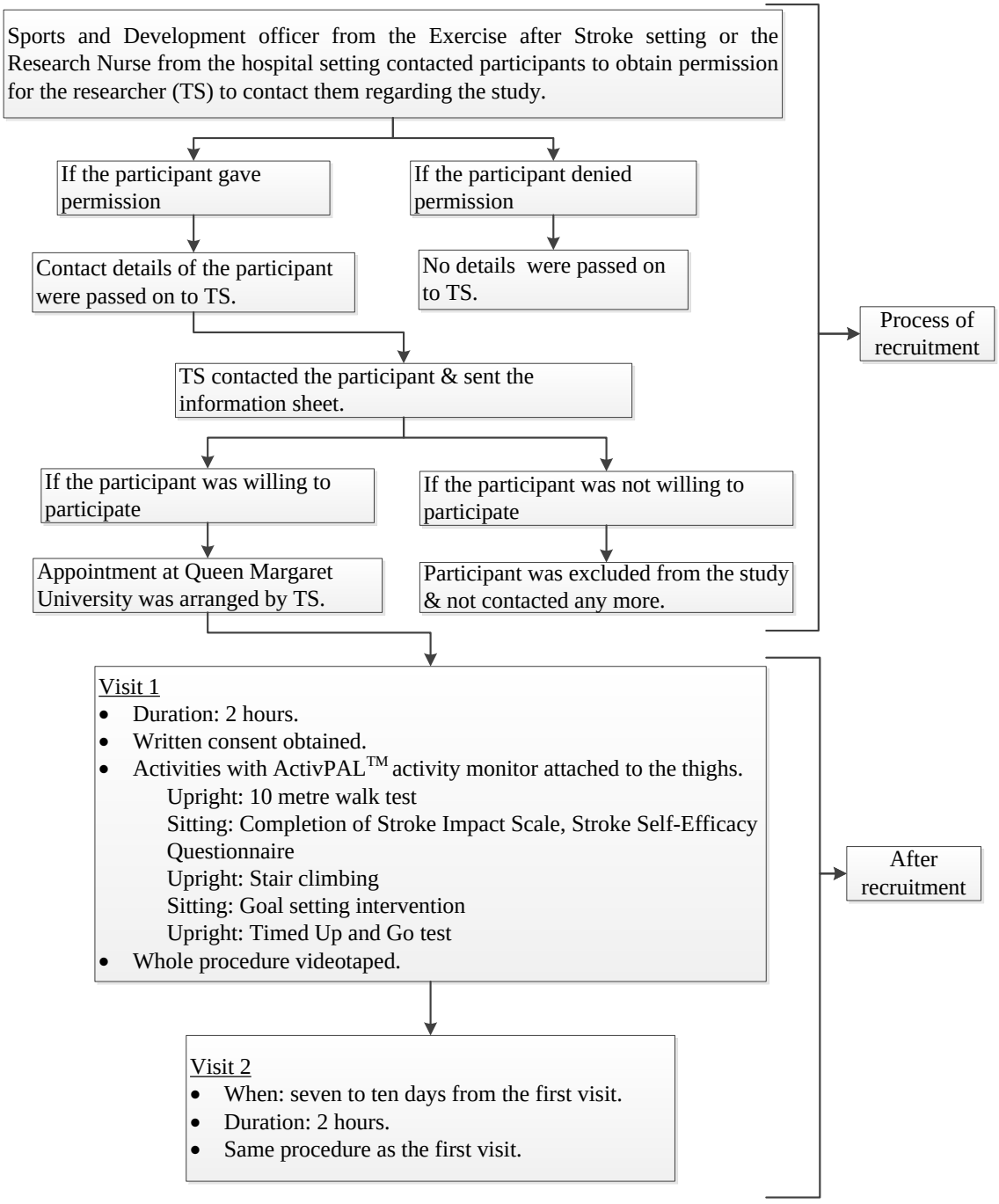

Figure 6.1: Flow chart of the study procedure followed for the pilot study

6.4.5. **Inclusion criteria**

6.4.5.1. Recruitment from Exercise after Stroke service

Any participant who was participating in the EaS class and able to provide informed consent was eligible to take part in the study. The Exercise after Stroke service is an exercise on referral scheme; hence clients must have been referred through the necessary channels (i.e. stroke specialist health professional). The criteria for referral to this service has been described earlier in chapter 2, section 2.5.

6.4.5.2. Recruitment from the hospital setting

A participant was recruited to the study if he or she fulfilled the following inclusion criteria of: (i) having a confirmed diagnosis of stroke, (ii) being medically stable, (iii) being able to walk 10 metres independently or with the help of a walking aid, (iv) being able to follow simple instructions by most appropriate method (verbal, visual cues and written), and (v) being able to provide informed consent.

Although participants were recruited from two different sources, the similarity in inclusion criteria for both ensured that the characteristics of the included participants remained similar.

6.4.6. **Exclusion criteria**

Participants who were not able to provide informed consent were excluded from the study.

6.4.7. **Study setting**

The study was conducted in the Gait Laboratory within QMU, Edinburgh.

6.4.8. **Study duration**

The participants were involved in this study for two weeks. They had two visits in this period, seven to ten days apart. Each visit lasted for a maximum of two hours, with breaks as requested by the participant.

6.4.9. **Pre-pilot work**

Since the study had multiple aims, several components were involved and therefore, pre-pilot work was done to finalise the study procedure (Appendix 10). Based on this work, the following decisions were made in relation to the study procedure:

(i) The activPAL™ would be active (i.e. switched on) for the entire duration of the study session rather than stopping it between tests.

(ii) Only one video camera would be used and this would be placed on the floor behind the chair in which the participant sat. All the activities would be performed within this straight line of vision by moving the required equipment, rather than by the participant moving between stations (e.g. for the participants to complete the questionnaires, the participants would remain sitting in the chair and the researcher would move a table close to the participant instead of the participant having to move towards the table).

(iii) A 20 second time period would be incorporated between transitions. However, this would not be done for the TUG test, as the test is a measure of time required to complete one continuous bout of activity.

(iv) The activPAL™ would be positioned at the following point: in standing, the length of the anterior aspect of the thigh between the anterior superior iliac spine and upper border of the patella would be measured and one third of this distance would be calculated. A photograph of a model with the activPAL™s positioned accordingly is presented as Figure 6.2 (written consent was obtained for publication of this photograph).

(v) For the video observation a step would be defined as, “the point of initial contact of the foot where mass is transferred to the next consecutive point of contact of that foot where mass is transferred (the consecutive point of contact of the foot does not necessarily have to be the same part of the foot)” (McAloon 2007, p.31). During shuffling or feet dragging, there would be no transference of mass between the feet and hence, this would not be counted as a step.

Figure 6.2: Model with the activPAL™ positioned on the anterior mid-thigh

6.4.11. **Equipment**

The following equipment was used for this study (Figure 6.3):

(1) ActivPAL™ monitor (PAL Technologies Ltd 2010)
(2) ActivPAL™ key (PAL Technologies Ltd 2010)
(3) ActivPAL™ Docking station
(4) 3M Tegaderm® film
(5) Digital camcorder (Sony® Hybrid model no: DCR-DVD 110E)
(6) DVD's (Fujifilm DVD-R)
(7) Digital stop-watch (TM20)
(8) Conventional rehabilitation stairs device (used in Physiotherapy departments to practice stair walking) consisting of three steps with a step height of 10cm and supported by hand rails.
(9) Chair with arm rest
(10) Password protected laptop.

Figure 6.3: Equipment used in the study

6.4.12. **Testing protocol**

The flowchart in Figure 6.1 provides an outline of the study protocol. The researcher conducted the interventions and all the assessments throughout this study.

Before data collection, the activPAL™s were connected to the laptop to synchronise the internal clock. The clock of the digital camcorder was also synchronised with the laptop.

During the first visit, the participants' questions were answered and written consent was obtained. Demographic data such as age, sex, time since stroke, affected side, and type of stroke were collected. The placement position for the activPAL™ was measured and marked. To begin data collection, a chair was placed at one end of the room and the participants were asked to sit in this chair (chair 1 in Figure 6.4). The digital camcorder was placed in position and switched on for recording. The activPAL™ was placed in position one on each leg and secured using a 3M Tegaderm® film. The right activPAL™ was switched on first using the key followed by the activPAL™ on the left leg. The study procedure comprised five stages, as mapped out in Figure 6.4 and explained in the following sub-sections.

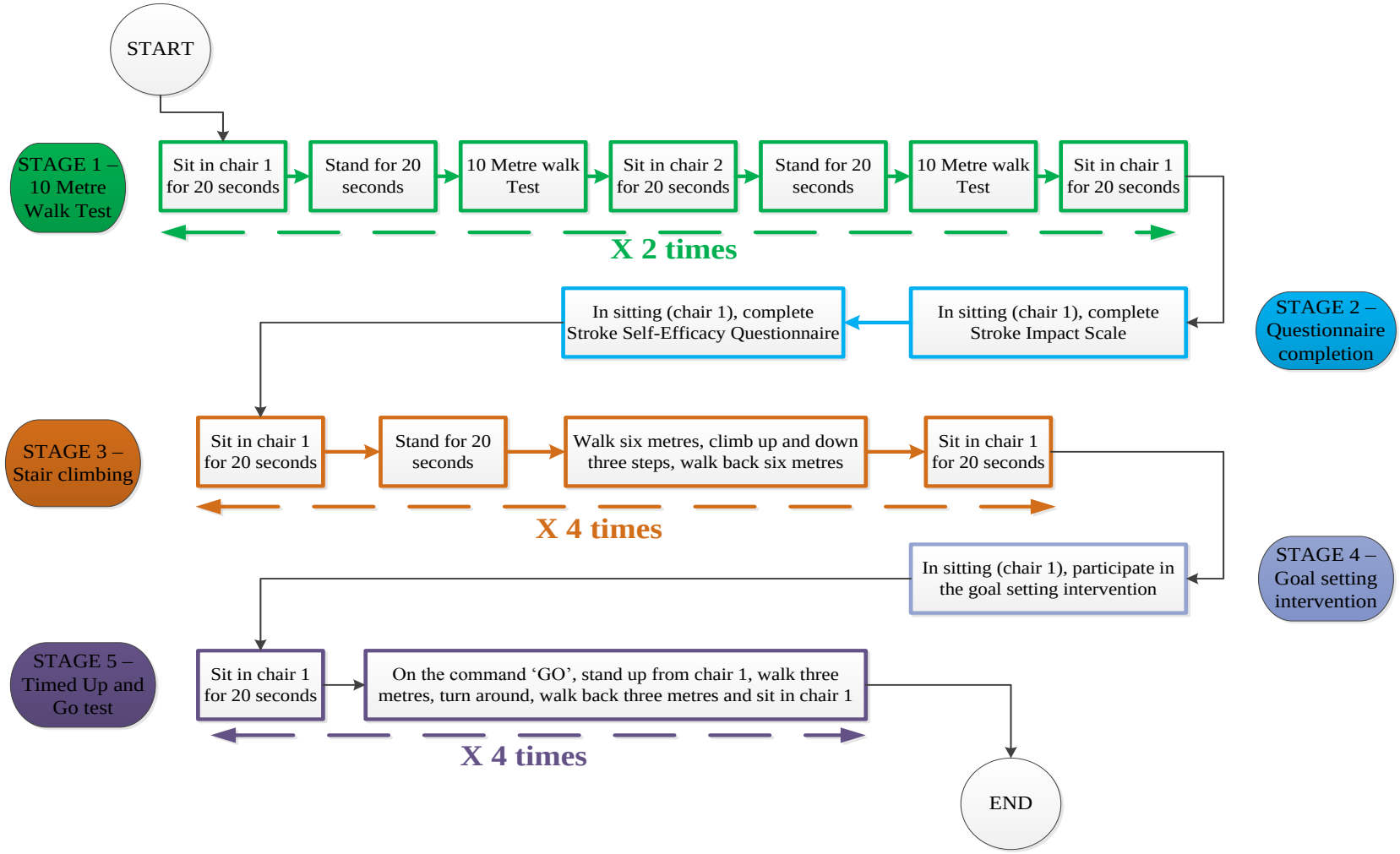

Figure 6.4: Pilot study procedure in stages

6.4.12.1. Stage one: 10 metre walk test

Data collection started with the 10MWT. The protocol proposed by Watson (2002) was followed for this test in this programme of work, as it was proposed for use with neurologically affected populations (Watson 2002). Accordingly, a start and finish line for a distance of ten metres was marked with a tape on the floor along a 14 metre walking space. The participants were asked to walk towards chair 2 at their usual walking speed. They were asked to use any walking aid that they normally used during walking. To measure the time taken to walk ten metres, the stop-clock was started at the moment when the participant's foot first crossed the marked start point of the ten metres and stopped when the foot crossed or touched the finish line. Although the protocol suggested a rest period of 20 seconds and three trials, for this programme of work, the participants performed four trials (as this allowed them to come back to their original starting point (chair 1) at the end of the test) and were asked to sit at the end of each trial. The participants sat in the chair for 20 seconds, then stood at the starting point for a further 20 seconds before starting the next trial. Therefore, a total of 40 seconds elapsed between each trial. This sitting period was incorporated as it was expected that some participants might find it difficult to complete four trials without a sitting period in-between.

6.4.12.2. Stage two: questionnaire completion

Next, participants completed the SSEQ and the SIS in sitting. If requested, the researcher read out the questions for the participants to answer and the answers were documented. While completing the SSEQ, the participants were reminded that the questions were about confidence in doing things rather than their actual performance to ensure the correct understanding and completion of the questionnaire.

6.4.12.3. Stage three: stair climbing

This was followed by the stair climbing component. After a 20 second period each of sitting and standing, participants walked a distance of six metres and climbed up three steps of a stair, turned around and descended the steps and walked backed to the chair. This was repeated four times.

6.4.12.4. Stage four: goal setting intervention

The person-centred goal setting intervention was delivered next. For this, the participants remained in sitting. The intervention procedure explained in chapter 5 was followed. However, it should be noted that in line with the aims of the current study, only the initial goal setting discussion was piloted, and not the intervention as a whole. Therefore, the participants did not use the goal setting workbook. Instead, the researcher introduced the workbook and showed it to the participants, and asked for their feedback on the layout, clarity, and accessibility. For participants who were referred from the hospital setting, information was provided about the EaS service first, before goal setting in relation to physical activity was discussed. During the second visit for the study (i.e. within two weeks from the first visit), the participants were asked about their plans or initial progress towards achieving the decided goals. However, due to the short time interval between visits, goal attainment was not discussed.

6.4.12.5. Stage five: the Timed Up and Go test

Finally, the TUG test was conducted. The researcher demonstrated the test first for clarity. A coloured tape was used on the floor to denote the end of three metres. The participants remained in sitting for 20 seconds. They were then instructed to get up from their chair, walk a distance of three metres, turn around and walk back and sit in the chair on the command “go”. A TM20 model digital stop-clock was used to record the time taken. The stop-clock was started on the word “go” and stopped when the participant was seated back in the chair with their back resting against the back of the

chair. The participants were asked to walk at their normal pace and use any walking aid that they normally used. If needed, the participants could stop, rest and continue the test. However, no physical assistance was provided to perform the test. With 20 seconds rest period in between, the test was repeated four times.

At the end of the test, the activPAL™ was switched off using the key: the right first, followed by the activPAL™ on the left. Finally, the digital camcorder was switched off. The same procedure was followed during the participant's second visit.

6.4.13. **Data reduction and analysis**

Demographic data, including age, sex, time since stroke, affected side, and type of stroke were collected and summarised descriptively for the group. The average gait speed (m/s) was calculated from the time taken to complete the 10MWT.

6.4.13.1. Reliability

Three types of reliability were considered in this study:

(i) Intra-observer reliability (i.e. the reliability of the researcher's video observations).
(ii) Inter-device reliability (i.e. the reliability between two activPAL™s of the same model).
(iii) Test-retest reliability (the reliability of the activPAL™ measurements over time).

6.4.13.1.1. Data reduction – intra-observer reliability

Since the video observation was to be used as the criterion measure to establish the concurrent validity of the activPAL™ monitor, it was essential to ensure accuracy of this criterion measure. Therefore, the video recording for each of the participant was viewed

by the researcher on three separate days, seven to ten days apart. To eliminate bias, the researcher was blinded to the previous measurements. These data was used to establish the intra-observer reliability.

6.4.13.1.2. Data reduction – inter-device reliability

To determine the inter-device reliability, all the relevant data from either the first visit or the second visit had to be chosen. To reduce any bias in selection, a ticket was randomly picked from a hat, and through this method the data collected during the first visit was chosen to be used for this analysis. Since the activPAL™ on the right leg was switched on first using the key, the values for time spent in sitting and total recording time were adjusted using the observations from the video. For example, if the activPAL™ on the right leg was switched on 30 seconds earlier than the activPAL™ on the left leg (as noted in the video), then these 30 seconds were subtracted from the time spent in sitting and total recording time. This was done to ensure that any changes noted in the measurements between the devices were not due to the monitors being switched on and off early or late. The inter-device reliability of the activPAL™ was calculated for all the measurements.

6.4.13.1.3. Data reduction – test-retest reliability

In order to determine the test-retest reliability, all the data from either the activPAL™ worn on the left leg or the right leg could be used. To reduce any bias in selection, a ticket was picked from a hat at random, and by this method, the data recorded by the activPAL™ on the left leg during both visits were chosen for this section of the analysis.

Although similar activities were conducted during both the visits, the time taken for these activities differed, which would have produced differences in the activPAL™ measurements between visits and hence was expected to have a profound effect on test-retest reliability. In order to alleviate the difference associated with this inevitable

human performance variability, and to be able to measure only the variability associated with the device, the following procedure was undertaken. The difference in timings between the video observations on the first visit and the second visit was considered, and the video observations of the second visit were equated to the first visit. For example, if the participant had spent an additional 30 seconds, 1 minute and 30 seconds in sitting, standing and stepping respectively in the second visit, this additional time was eliminated from the second visit timings. These additional times were subtracted/added to the second visit readings of the activPAL™. These equated activPAL™ measurements were then used for the evaluation of the test-retest reliability of the activity monitor. The test-retest reliability of the activPAL™ was calculated for all the measurements.

6.4.13.1.4. Data analysis - reliability

As recommended by Atkinson and Nevill (1998) both relative reliability and absolute reliability have been considered in this study. Relative reliability has been described as "the degree to which individuals maintain their position in a sample over repeated measurements", while absolute reliability is "the degree to which repeated measurements vary for the individual" (Atkinson Nevill 1998, p.219).

Relative reliability – Intraclass Correlation Coefficient (ICC)

To establish relative reliability, the Intraclass Correlation Coefficient (ICC) at 95% Confidence Intervals (CI) was used (Atkinson and Nevill 1998, Bruton et al. 2000).

The ICC (2,1) was selected for the following reasons. Firstly, the data fitted as a 2-way model because the two devices were used for all the participants for all the trials. Secondly, since generalisability of the results was required, a random effects model was chosen. Moreover, it was essential to consider both systematic and random error. Therefore, case 2 of the ICC was selected. Finally, as only single measurements were

used rather than mean values, the integer of 1 was chosen (Weir 2005, Shrout and Fleiss 1979). The levels of reliability were determined as: 1 - 0.81→ perfect, 0.80 - 0.61 → substantial, 0.60 - 0.41 → moderate, 0.40 - 0.21 → fair, and 0.20 - 0.00 → slight (Landis and Koch 1977).

Absolute reliability – SEM

To establish absolute reliability, standard error of measurement (SEM) was used (Atkinson and Nevill 1998, Weir 2005, Hopkins 2000). Most authors support the use of SEM for absolute reliability, since the statistic is expressed in the actual unit of measurement and is easy to interpret. The use of other methods such as Bland and Altman's limits of agreement (LOA) is still under debate. Some authors value it for the graphical representation, while others argue against it due to the difficulty in its interpretation (Atkinson and Nevill 1998, Weir 2005, Hopkins 2000). Therefore, the SEM was chosen for this study.

The SEM was calculated using the formula below:

$$\mathrm{SEM}=\mathrm{SD}\sqrt{1\text{-}\mathrm{ICC}}$$

The two tests (ICC and SEM) were used to determine both inter-device reliability and test-retest reliability of the activPAL™.

6.4.13.2. Concurrent validity

6.4.13.2.1. Data reduction - concurrent validity

Although similar data were collected from the participants on two occasions (in order to be able to evaluate the test-retest reliability of the monitor), only the data collected during the first visit were used to examine validity. Again, although two monitors were used in each visit (one on each leg for the purpose of inter device reliability), only the data from one activPAL™ were used to examine validity. The inter-device reliability of

the activPAL™ was not known before the start of the data collection. Therefore, to ensure accuracy, one activPAL™ was chosen to be worn on the left leg and one for the right leg, for all the participants throughout the study. Hence, the selection of the monitor for evaluating validity had to be made based on the side the monitor was worn (i.e. the right leg or left leg) rather than the affected/non-affected side. To reduce any bias in this selection, a ticket was randomly picked from a hat, and by this method, the activPAL™ worn on the left leg was chosen to examine concurrent validity. The full range of activPAL™ parameters were considered, which included: number of steps, time spent in sitting, time spent in standing, time spent in stepping, time spent upright, and number of transitions (sit-to-stand and stand-to-sit).

6.4.13.2.2. Data analysis – concurrent validity

The distribution of the data was determined using the Shapiro-Wilk test as the study had fewer than 50 data points.

Bland and Altman analysis

Concurrent validity was established using Bland and Altman 95% LOA as this test shows agreement between two variables (Bland and Altman 1986). In the current study, the test was used to determine the agreement between the activPAL™ monitor and video observation in order to establish concurrent validity. Other tests, such as correlational tests, only assess relationships between variables, and it has been demonstrated that variables that correlate well with each other do not necessarily show good agreement (Bland and Altman 1986).

The mean of the two methods (video and activPAL™) and the difference between the two methods (video – activPAL™) were calculated for each participant for all the above mentioned measurements, and plotted graphically. Then, the mean (estimated bias) and

the standard deviation (SD) of the differences between the two methods were calculated, from which 95% LOA were derived using the formula below:

$$95\%\ \text{limits of agreement} = \text{Estimated bias} \pm (1.96 \times \text{SD})$$

$$\text{where estimated bias} = \text{mean of the difference between the two methods}$$

The lines of reference for the estimated bias, upper LOA (ULOA) and lower LOA (LLOA) were finally added to the plotted graph.

Bland and Altman (1986) do not provide a specific guide to help in the interpretation of the data. It is generally stated that an estimated bias closer to zero and a narrow limits of agreement denote good agreement between two variables (Bland and Altman 1986).

Percentage error

Although the Bland and Altman analysis provides the bias and LOA, the bias calculated is only the estimated bias. Therefore, the magnitude of error is not known from this analysis. Moreover, the interpretation of the LOA is subjective (Atkinson and Nevill 1998, Bland and Altman 1986). Hence, to provide clearer estimates of the error, and help with the interpretation of error magnitude, percentage error (PE) of the data was also calculated and analysed.

The PE of the estimated bias for each measurement was calculated by dividing the estimated bias by the mean of the measurements from the video observation (i.e. number of steps, time spent in sitting, time spent in standing, time spent in stepping, time spent upright, and number of transitions) and multiplied by 100.

6.5. **Results**

The recruitment and sample characteristics of the whole group are presented first, followed by the results regarding the piloting testing of the goal setting intervention and familiarisation with the outcome measures. The results for the accuracy of the activPAL™ activity monitor are described in the following order: intra-observer reliability, inter-device reliability, and concurrent validity. The data collected from all the participants are attached as an electronic appendix (CD-ROM).

6.5.1. **Recruitment**

The plan was to recruit a minimum of 15 participants for this study. During the initial contact with the authorities of the EaS service, this number was identified as feasible. Some previous validation studies with the activPAL™ were also conducted with similar numbers (Grant et al. 2006, Ryan et al. 2006). However, several recruitment problems were encountered. Although the EaS authorities emphasised that all potential participants were contacted, they refused to share any information regarding the numbers contacted, and reasons for refusal, due to data protection issues. Therefore, recruitment from a hospital setting was included as an additional source of recruitment. However, the targeted population in the hospital were being recruited for other studies at the same time, and this impacted on the recruitment to the current study. Due to the time restrictions of the PhD programme, recruitment had to be stopped before achieving the desired sample size.

Over the recruitment period, ten participants referred through the EaS service were approached by the researcher, of which five agreed to participate (recruitment of 50%). Reasons for non-participation included: lack of interest (n=2) and lack of time (due to household responsibility (n=1) and return to full-time work (n=2)). Of the 13 participants referred from the hospital setting, seven agreed to participate (recruitment of

53%). Reasons for non-participation included: lack of interest (n=3), lack of recovery from stroke (n=3), and lack of time (n=1).

6.5.2. **Sample characteristics**

A total of 12 participants (three females, nine males) were recruited, with a mean age of 63.7 ± 13 years. The mean time that had elapsed since the occurrence of their stroke was 16.2 months ± 22.1 months. The mean gait speed for the participants was 0.72 ± 1.38 m/s. The individual demographics of the participants are presented in Table 6.1.

Of the 12 participants, one male participant did not attend the second session due to personal reasons and therefore this participant was not included in the analysis of test-retest reliability. The data collected in the first visit were used in the analysis of concurrent validity and inter-device reliability, after consent was obtained from the participant.

Table 6.1: Individual demographics of the participants in the pilot study

Key: FES – Functional Electrical Stimulation.

Participant number	Age(years)	Sex	Time since stroke (months)	Affected body side	Handedness	Type of stroke	Use of walking aids / Assistive devices	Gait Speed (m/s)
1	71	Female	19	Right	Right	Ischaemic	FES (right leg), walking stick (left side)	0.6
2	86	Male	32	Left	Right	Ischaemic	None	0.9
3	70	Male	77	Left	Right	Ischaemic	FES (left leg), walking stick (right side)	0.3
4	74	Female	31	Left	Right	Ischaemic	None	0.9
5	73	Female	4	Left	Right	Ischaemic	None	0.9
6	57	Male	4	Left	Right	Ischaemic	None	0.8
7	41	Male	2	Right	Right	Ischaemic	None	1.2
8	53	Male	8	Left	Right	Ischaemic	None	1.1
9	46	Male	8	Left	Right	Ischaemic	Walking stick (right side)	0.5
10	65	Male	7	Right	Right	Ischaemic	None	0.7
11	71	Male	1	Right	Right	Ischaemic	None	1.2
12	57	Male	1	Left	Right	Ischaemic	None	1.2

6.5.3. **Pilot testing of the goal setting intervention**

The person-centred goal setting intervention was applied to all the participants as part of their activity in sitting. The researcher was able to deliver the intervention as intended (i.e. initiate discussions on goal setting, help participants to identify problems by providing examples, ensure participant understanding at different points, and clear explanation of the different components of the COPM). Two participants (one male and one female) had mild communication impairments, however, carers of both these participants were present during the discussions to help, and therefore, their participation in goal setting was not affected. When the participants were shown the goal setting workbook and were asked to comment on it, various positive comments were received. This included: "interesting", "useful", "good pictures", and "I like it". Questions were asked as to whether the researcher would provide help to complete the workbook, and if help could be obtained from carers for completing the workbook. The researcher explained that instruction and help would be provided during the initial stages, and that the participants would be encouraged to develop the weekly goals by themselves as part of ownership of goals and self-management. However, it was emphasised that help would be provided at all stages if required. It was also clarified that carers could help the participants with the workbook completion. No negative comments were received. All participants were able to identify at least one goal relating to physical activity, the most common being able to walk to a near-by bus-stop (n=5). However, some participants required more probing than the others, and took a longer time to decide on their goals.

6.5.4. **Familiarisation with the outcome measures**

All participants were able to complete the 10MWT and the TUG test without any difficulty. All participants completed the two questionnaires, however, four participants requested that the questions be asked by the researcher, rather than them reading them directly, due to difficulty with reading. The researcher became familiarised with the procedures involved in these outcome measures, ensuring fidelity.

6.5.5. **Intra-observer reliability**

The intra-observer reliability of video observation for all the measures (number of steps, time spent in sitting, standing and stepping, and number or sit-to-stand and stand-to-sit transitions) was perfect, with ICCs ranging between 0.997 and 1. The SEM was zero for all the measurements excluding the time spent in standing (SEM=0.02). The individual ICC value for each measurement, the 95% confidence intervals and the corresponding SEM are presented in Table 6.2.

Table 6.2: Intra-observer reliability of video observation (measured over three occasions)

Key: ICC – Intra Class Correlation; SEM – Standard Error of Measurement.

Measurement	ICC (2,1) values	95% confidence intervals		SEM
		Lower bound	Upper bound	
Number of steps	1	1	1	0 steps
Time spent in sitting	1	1	1	0s
Time spent in standing	0.997	0.991	0.999	0.02s
Time spent in stepping	1	1	1	0s
Time spent upright	1	1	1	0s
Sit-to-stand transitions	1	1	1	0 transitions
Stand-to-sit transitions	1	1	1	0 transitions

6.5.6. **Inter-device reliability**

The inter-device reliability for all the measurements was perfect, with ICCs ranging between 0.901 and 1. The SEM for the times spent in different positions and for the

number of transitions was less than 1. However, the SEM for the number of steps was 25.5 steps. The individual ICC value for each measurement, the 95% confidence intervals and the corresponding SEM are presented in Table 6.3.

Table 6.3: Inter-device reliability of the activPAL™

Key: ICC – Intra Class Correlation; SEM – Standard Error of Measurement.

Measurement	ICC (2,1) values	95% confidence intervals		SEM
		Lower bound	Upper bound	
Number of steps	0.972	0.905	0.992	25.5 steps
Time spent in sitting	1	0.999	1	0s
Time spent in standing	0.979	0.929	0.994	0.1s
Time spent in stepping	0.998	0.994	0.999	0.1s
Time spent upright	0.999	0.997	1	0.1s
Sit-to-stand transitions	0.979	0.928	0.994	0.3transitions
Stand-to-sit transitions	0.901	0.693	0.970	0.6transitions

6.5.7. **Test-retest reliability**

The ICC values for all measurements, excluding the number of transitions, were perfect (range between 0.885 and 0.999) (Table 6.4). The test-retest reliability of the sit-to-stand transitions was only moderate (ICC=0.489), while the test-retest reliability of the stand-to-sit transitions was substantial (ICC=0.660). The SEM scores were less than one for the measurements of time spent in different positions, while the number of transitions had a SEM slightly greater than one (Table 6.4). However, the SEM for the number of steps was 34.6 steps.

Table 6.4: Test-retest reliability of the activPAL™

Key: ICC – Intra Class Correlation; SEM – Standard Error of Measurement.

Measurement	ICC (2,1) values	95% confidence intervals		SEM
		Lower bound	Upper bound	
Number of steps	0.951	0.828	0.987	34.6 steps
Time spent in sitting	0.999	0.998	1	0.4s
Time spent in standing	0.885	0.629	0.968	0.3s
Time spent in stepping	0.965	0.875	0.990	0.4s
Time spent upright	0.965	0.876	0.990	0.5s
Sit-to-stand transitions	0.489	-0.120	0.831	1.2transitions
Stand-to-sit transitions	0.660	0.136	0.896	1.1transitions

6.5.8. **Concurrent validity**

On average, the participants performed the various activities for a duration of 60.6 ± 14.3 minutes. The results for concurrent validity of the activPAL™ for the number of steps taken, time spent in sitting, standing, stepping, time spent upright, and number of transitions are presented in the following sub-sections.

6.5.8.1. Number of steps

From the video observation it was estimated that the participants took a total of 347 ± 158 steps in this study. The estimated bias between the video observation and activPAL™ was 67.5 steps (PE = 19.4%), which meant that the activPAL™ underestimated the number of steps taken by the participants. Since the estimated bias (mean of the differences) and the SD (25.2 steps) were high, the ULOA (117 steps) and LLOA (18 steps) were wide (Figure 6.5), highlighting the poor agreement between the two methods for this measurement.

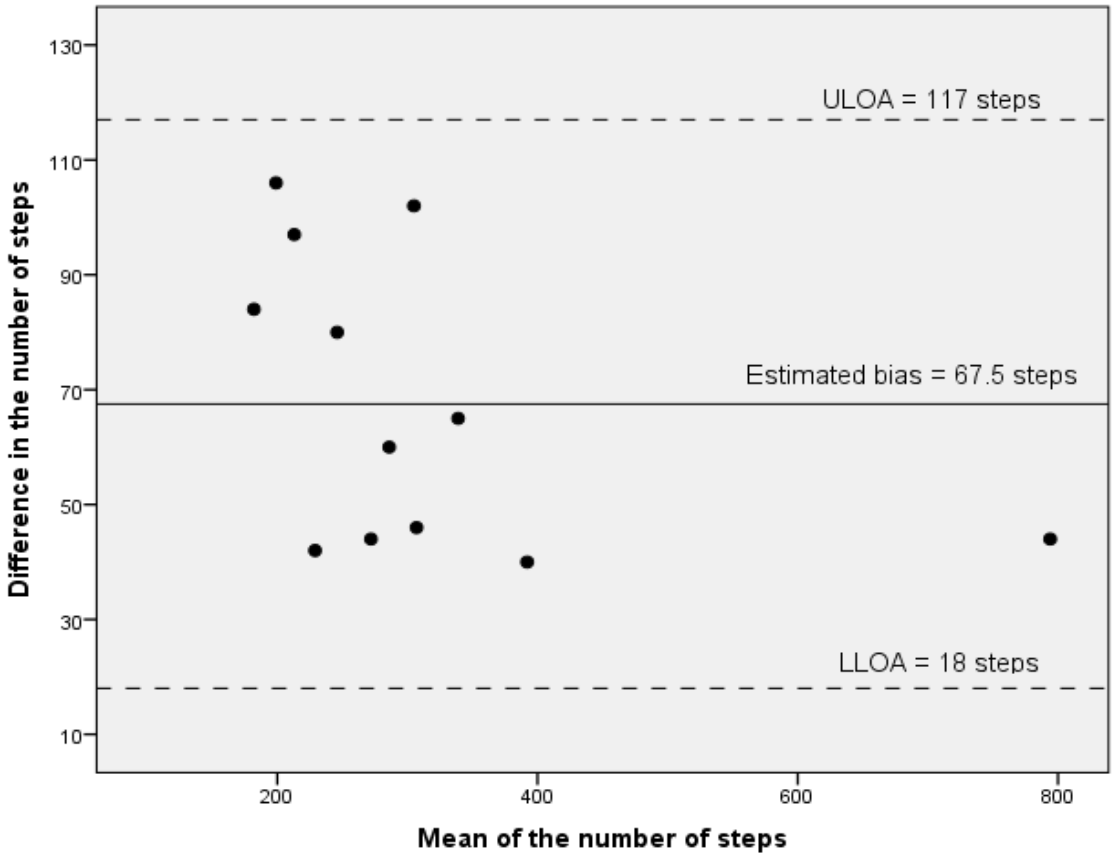

Figure 6.5: Agreement between activPAL™ and video observation for total number of steps

Key: ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

A further analysis of the number of steps taken during each of the walking activities (10MWT, stair climbing, and TUG test) was undertaken. The estimated bias, SD, LOA and PE for each of these activities is presented in Table 6.5. The PE was highest for the TUG test at 37.4%, while the 10 metre walk test had a PE of 11.1% and the stair climbing activity had a PE of 15.9%.

Table 6.5: Concurrent validity of the activPAL™ for number of steps for each walking activity

Key: LLOA – Lower Limits of Agreement; LOA – Limits of Agreement; PE – Percentage Error; SD – Standard Deviation; ULOA – Upper Limits of Agreement.

Walking activity	Average number of steps (for four trials each) ± SD	Estimated bias ± SD	LOA		PE (%)
			ULOA	LLOA	
10 metre walk test	114.5 ± 53.8	12.7 ± 4.7	21.8	3.5	11.1
Stair climbing	150 ± 61.4	23.8 ± 8.9	41.2	6.5	15.9
Timed Up and Go test	82.8 ± 43.5	31 ± 21.7	73.4	-11.4	37.4

6.5.8.2. Time spent in sitting

From video observation, participants spent an average of 52.9 ± 13.2 minutes in sitting. Figure 6.6 illustrates the agreement between the activPAL™ and video observation for the time spent in sitting. From the figure, it can be seen that the estimated bias (mean of differences) was +0.1 minutes (PE = 0.2%), with a SD of 0.5 minutes. The upper and lower limits of agreement were +1.1 and -0.8 minutes, respectively. All the data points were within the LOA.

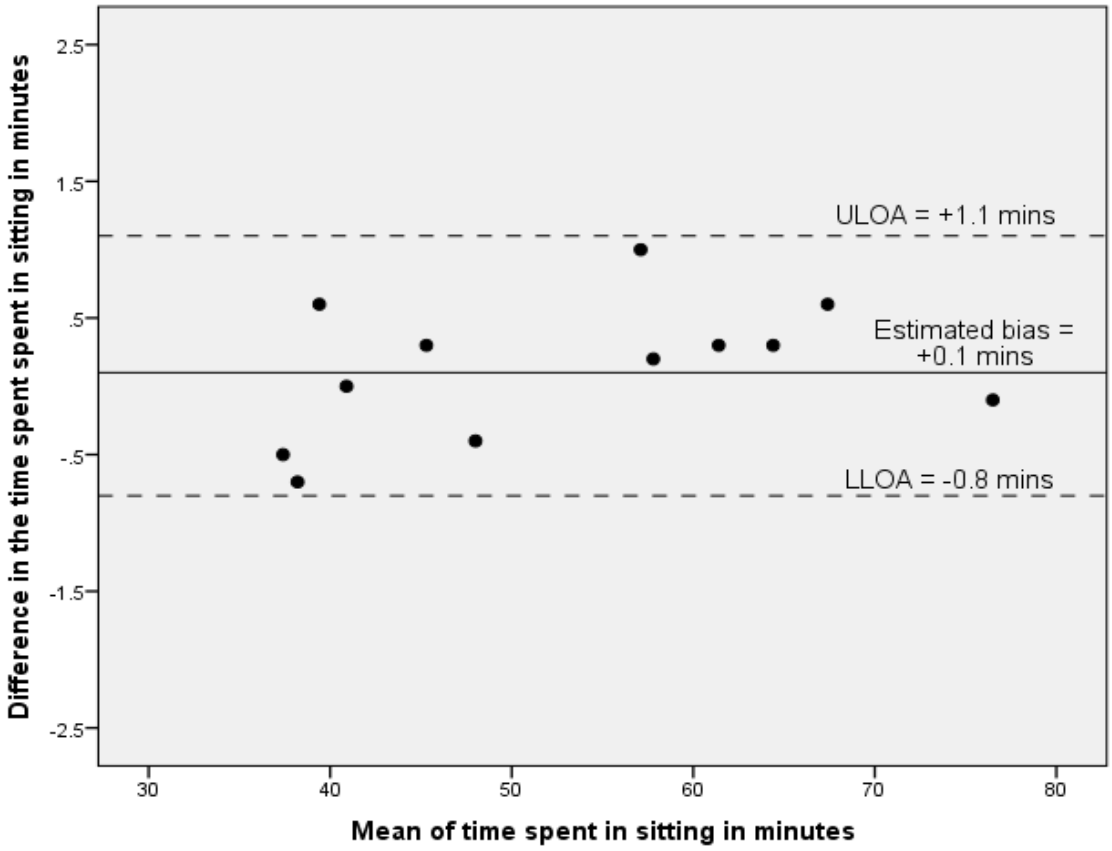

Figure 6.6: Agreement between activPAL™ and video observation for time spent in sitting

Key: ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

6.5.8.3. Time spent in standing

On average, the participants spent 3.1 ± 0.3 minutes in standing. The agreement between the activPAL™ and video observation is presented in Figure 6.7. The estimated bias was -1.0 minutes and SD of the bias was 0.6 minutes, inferring that the activPAL™ overestimated the standing time by 1 ± 0.6 minutes (PE = 32.9%). The limits of agreement were narrow (ULOA +0.1 minute, LLOA -2.1 minutes). There were no

outliers. Most of the data points were clustered close to the estimated bias in the positive direction, confirming the overestimation of the activPAL™. Interestingly, it appears that as the time spent in standing increases, so does the difference between the two measures in the negative direction i.e. the overestimation.

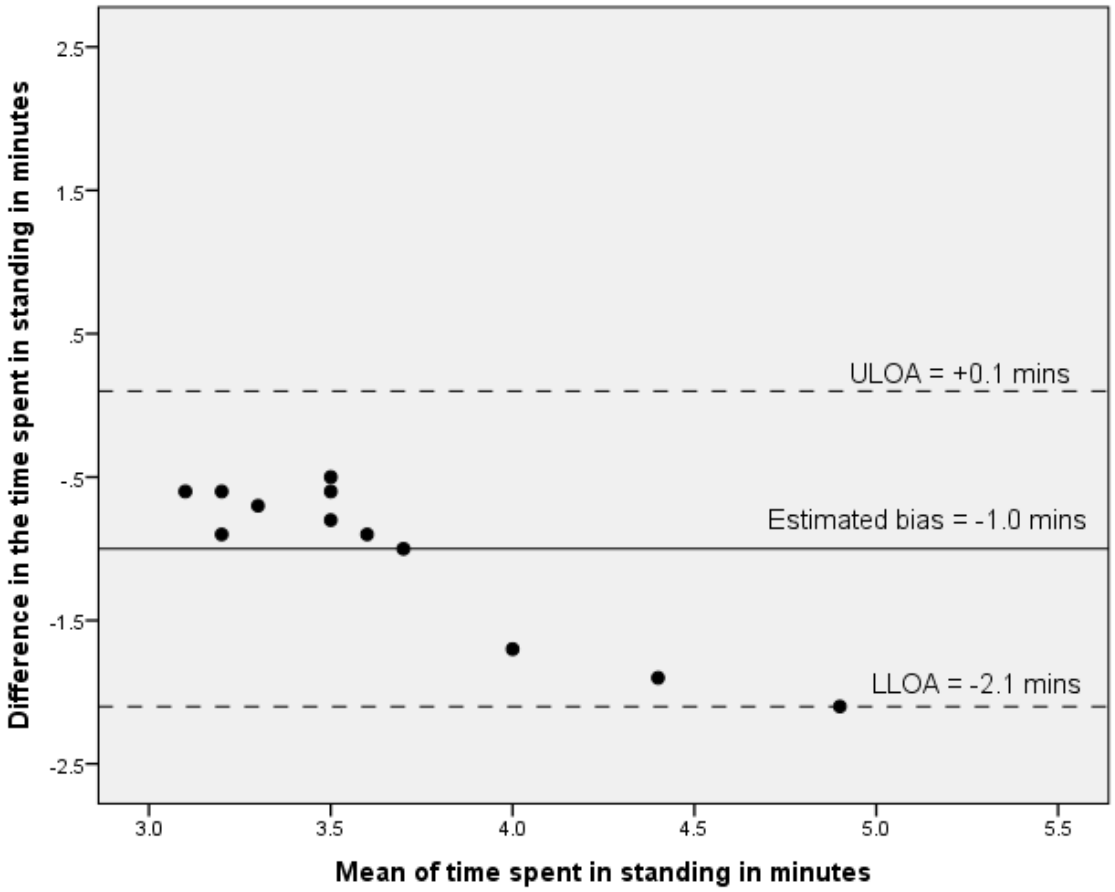

Figure 6.7: Agreement between activPAL™ and video observation for time spent in standing

Key: ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

6.5.8.4. Time spent in stepping

The participants spent a total of 4.7 ± 2.3 minutes (from video observation), on average, in stepping. The estimated bias and the ULOA and LLOA are illustrated in Figure 6.8. The mean of the differences was 1.3 minutes, indicating that the activPAL™ underestimated the stepping time by 1.3 ± 0.5 minutes (PE = 27.2%). The limits of agreement were narrow (ULOA = +2.2 minutes; LLOA = +0.3 minutes). The data were scattered, with no definite pattern; however, all data were within the LOA.

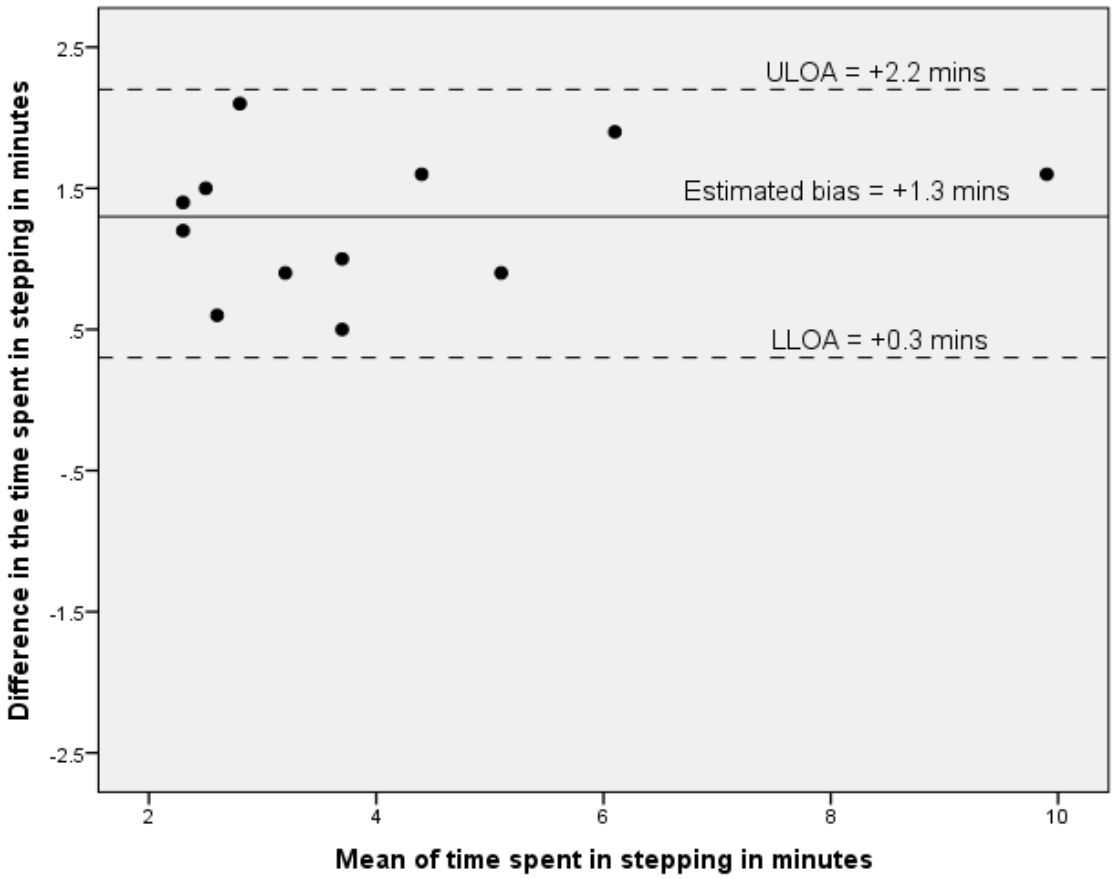

Figure 6.8: Agreement between activPAL™ and video observation for time spent in stepping

Key: ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

6.5.8.5. Time spent upright

The times spent in standing and stepping were added to determine the time spent upright. On average, the participants spent 7.8 ± 2.5 minutes upright. The estimated bias was 0.2 minutes (PE = 3.1%), with a SD of 0.6 minutes, inferring that the activPAL™ underestimated the time spent upright by 0.2 ± 0.6 minutes (Figure 6.9). The limits of agreement were narrow (ULOA = +1.4 minutes; LLOA = -0.9 minutes), indicating that the two methods have very good agreement (Figure 6.9). One data point was outside the LOA at +1.5 minutes, however, this was very close to the ULOA and its effects on the LOA were expected to be minimal.

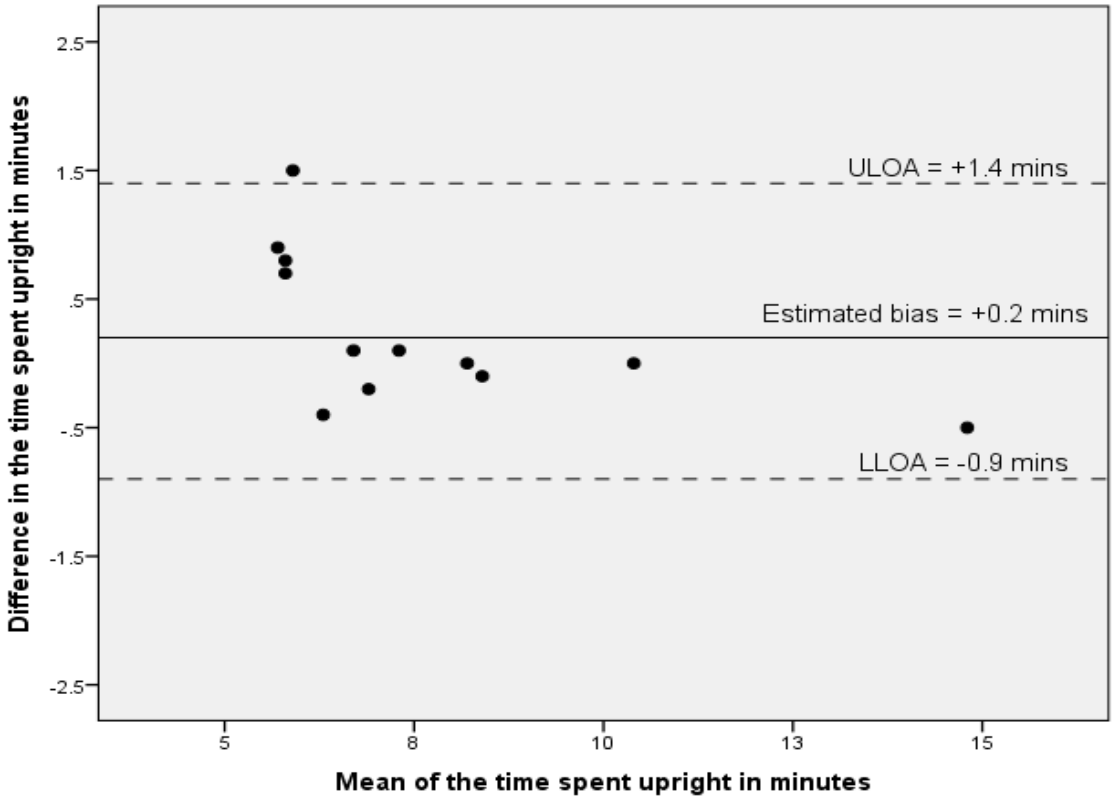

Figure 6.9: Agreement between activPAL™ and video observation for time spent upright

Key: ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

6.5.8.6. Number of transitions

On average, the participants performed 12 (SD = 0) sit-to-stand transitions and 12 stand-to-sit transitions (SD = 0). The activPAL™ underestimated the sit-to-stand transitions by 1.4 transitions (PE = 11.5%) (Figure 6.10) and the stand-to-sit transitions by 2.8 transitions (PE = 23%) (Figure 6.11). The LOA of agreement were wide for both these measurements: sit-to-stand transitions: ULOA = +5.3 and LLOA = -2.5 transitions (Figure 6.10); stand-to-sit transitions: ULOA = +6.9 and LLOA = -1.2 transitions (Figure 6.11).

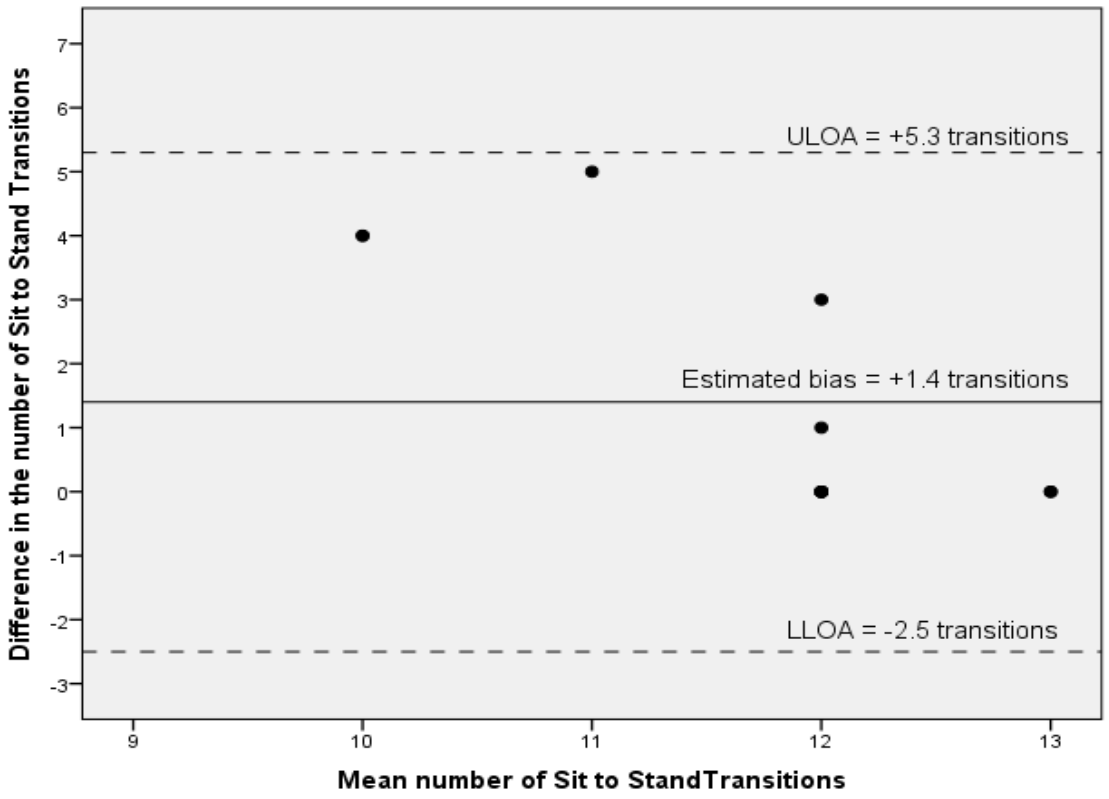

Figure 6.10: Agreement between activPAL™ and video observation for the number of sit-to-stand transitions

Key: Data from all 12 participants included. Some points overlap; ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

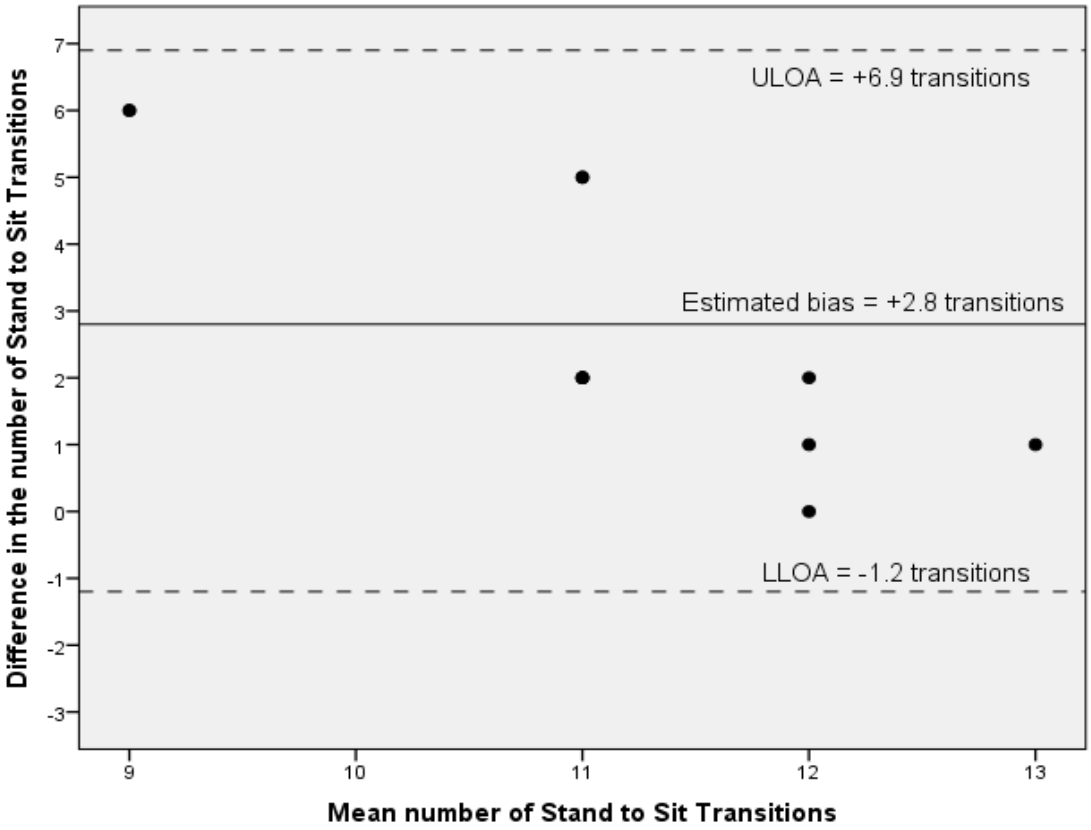

Figure 6.11: Agreement between activPAL™ and video observation for the number of stand-to-sit transitions

Key: Data from all 12 participants included. Some points overlap; ULOA- Upper Limits of Agreement; LLOA – Lower Limits of Agreement.

6.5.8.7. Summary

The results for the concurrent validity of the activPAL™ are summarised and presented as Table 6.6.

Table 6.6: Summary of results for concurrent validity of the activPAL™

Key: LLOA – Lower Limits of Agreement; LOA – Limits of Agreement; PE – Percentage error; SD – Standard Deviation; TUG – Timed Up and Go; ULOA – Upper Limits of Agreement; * - A positive bias means underestimation by the activPAL™ on comparison with the video observation.

Measurement variable	Estimated bias	SD of estimated bias	LOA		PE of estimated bias
			ULOA	LLOA	
Number of steps	67.5*	25.2	117	18	19.4%
Time spent in sitting (minutes)	0.1*	0.5	1.1	-0.8	0.2%
Time spent in standing (minutes)	-1.0	0.6	0.1	-2.1	32.9%
Time spent in stepping (minutes)	1.3*	0.5	2.2	0.3	27.2%
Time spent upright (minutes)	0.2*	0.6	1.4	-0.9	3.1%
Number of sit-to-stand transitions	1.4*	2.0	5.3	-2.5	11.5%
Number of stand-to-sit transitions	2.8*	2.1	6.9	-1.2	23%

6.5.9. **Concurrent validity – Affected and non affected limbs**

As explained in section 6.4.13.2.1, the same activPAL™s were worn on the left and right leg by all the participants and analysis for the concurrent validity was conducted using the activPAL™ worn on the left leg. Since the ICCs indicated that the inter-device reliability of the activPAL™ was excellent for all the variables measured, it was decided

that a secondary analysis would be conducted of the concurrent validity of the activPAL™ based on the monitor placement on the affected and non-affected limb. This was done to identify if the measured variables were affected by placement of the monitor on the affected limb versus the non-affected limb. The results of this secondary analysis (estimated bias, SD, LOA and PE) are presented in Table 6.7.

Table 6.7: Concurrent validity of the activPAL™ based on placement on affected or non-affected limb

Key: LLOA – Lower Limits of Agreement; LOA – Limits of Agreement; PE – Percentage error; SD – Standard Deviation; TUG – Timed Up and Go; ULOA – Upper Limits of Agreement; * - A positive bias means underestimation by the activPAL™ on comparison with the video observation.

Measured variables	ActivPAL™ placement	Estimated bias ± SD	LOA		PE (%)
			ULOA	LLOA	
Number of steps	Affected limb	*66.3 ± 24.5	114.3	18.4	19.1
	Non-affected limb	*77.7 ± 38.4	153.0	2.4	22.4
Time spent in sitting (minutes)	Affected limb	*0.2 ± 0.5	1.1	-0.7	0.3
	Non-affected limb	*0.1 ± 0.6	1.2	-1.0	0.2
Time spent in standing (minutes)	Affected limb	-1.0 ± 0.5	0.0	-2.1	33.2
	Non-affected limb	-1.0 ± 0.5	0.0	-2.1	33.2
Time spent stepping (minutes)	Affected limb	*1.2 ± 0.5	2.3	0.2	26.5
	Non-affected limb	*1.3 ± 0.5	2.2	0.3	27.2
Time spent upright (minutes)	Affected limb	*02 ± 0.6	1.3	-0.9	2.6
	Non-affected limb	*0.2 ± 0.6	1.3	-0.9	2.8
Number of sit-to-stand transitions	Affected limb	*1.3 ± 1.8	4.9	-2.2	10.8
	Non-affected limb	*1.3 ± 2.0	5.3	-2.6	10.8
Number of stand-to-sit transitions	Affected limb	*2.5 ± 2.2	6.8	-1.8	20.3
	Non-affected limb	*3.1 ± 1.8	6.7	-0.5	25.0

6.5.10. **Reliability of the 10MWT and the TUG test**

The 10MWT and the TUG test were used in this study with the main aim of gaining familiarity with the application of these measures. Although the psychometric properties of these tests have been published elsewhere (refer to section 2.9.2 and 2.9.3), it is useful to examine the reliability in the specific settings in which the study was conducted , in order to interpret any changes in outcomes as a result of the intervention. Therefore, an analysis of the intra-rater reliability and test-retest reliability properties of both these measures was undertaken using the same methods employed in the analysis of activPAL™ data (refer to section 6.4.13.1). From Table 6.8, it could be seen that both outcome measures had excellent reliability properties.

Table 6.8: Test-retest reliability of the 10MWT and the TUG test

Key: 10MWT – Ten metre walk test; TUG – Timed Up and Go;
ICC – Intra Class Correlation; SEM – Standard Error of Measurement.

Outcome measure	Property tested	ICC (2,1) values	95% confidence intervals		SEM (s)
			Lower bound	Upper bound	
10MWT	Intra-rater reliability	0.974	0.937	0.992	1.40
	Test-retest reliability	0.997	0.989	0.999	0.42
TUG test	Intra-rater reliability	0.968	0.922	0.990	1.43
	Test-retest reliability	0.992	0.970	0.998	0.71

Using the SEM values and 95% confidence interval, the minimal detectable change (MDC) (i.e. the amount by which a patient's score needs to change to be sure the change

is greater than measurement error (Donoghue et al. 2009)) was calculated using the formula below:

$$MDC = 1.96 * SEM * \sqrt{2}$$

A MDC value of 1.17 seconds was obtained for the 10MWT and 1.97 seconds for the TUG test. The mean gait speed was calculated from the 10MWT and using the above formula, a MDC of 0.14m/s was obtained for mean gait speed.

6.6. **Discussion**

The pilot study had three aims. The results for each of these aims are summarised and discussed in the following sub-sections.

6.6.1. **Pilot testing the person-centred goal setting intervention**

One of the aims of the study was to pilot test the person-centred goal setting intervention. Discussing and helping the participants to identify their own goals provided the researcher with the necessary interaction skills and instilled confidence to conduct this intervention as the main intervention in the next study (study four) of this programme of work. The intervention was applied to all participants without any difficulties. Therefore, no changes were made to the intervention and the workbook for the next study.

6.6.2. **Familiarisation with the other outcome measures**

Another aim of the study was to ensure fidelity of the selected outcome measures. In line with this, procedures as per protocol were followed for all the measures for all participants. No difficulties were encountered with the application of any of the outcome measures, and hence it was decided to use these outcome measures for the next study (study four).

The reliability properties (intra-rater and test-retest) of the 10MWT and the TUG test were demonstrated and these were in line with the results of the published literature (Wolf et al. 1999, Collen et al. 1990, Podsiadlo and Richardson 1991, Steffen et al. 2002) (section 2.9.2 and 2.9.3). The calculated MDC values could be used to interpret and discuss findings from these measures in the next study (study four).

6.6.3. **Validation of the activPAL™ activity monitor**

The third aim of this pilot study was to determine the validity and reliability of the activPAL™ activity monitor. Within this aim, four specific research questions were identified. The results of the intra-observer reliability of the video observation are discussed first, followed by the discussion of the validity and reliability for each of the variables measured.

6.6.3.1. Intra-observer reliability of video observation

One of the questions related to the intra-observer reliability of video observation to justify its use as the criterion measure for determining psychometric properties of the activPAL™. The perfect ICC scores and low SEMs confirmed the use of video observation as a criterion measure. Most of the studies which had evaluated the psychometric properties of the activPAL™ had used video observation as the criterion measure and had justified its use by establishing inter-observer reliability (Grant et al. 2008, Grant et al. 2006, Ryan et al. 2006, Ryan et al. 2008, Choo et al. 2011). However, to our knowledge, no studies have described intra-observer reliability of video observation, and the findings of this current study contribute to the evidence base in this field.

6.6.3.2. Number of steps

6.6.3.2.1. Concurrent validity

The number of steps recorded by the activPAL™ had a very high estimated bias and wide limits of agreement on comparison with video observation (Table 6.6 and Figure 6.5), thereby implying that the two measurements are not in agreement with each other. The activPAL™ underestimated the step count by 67.5 steps. The high PE (19.4%) also confirmed the lack of agreement between the two methods.

Other studies in healthy young populations (Ryan et al. 2006, Baer and O'Loughlin 2007, Choo et al. 2011, Kanoun 2009, Maddocks et al. 2010, Tsavourelou et al. 2009), healthy older adults (Grant et al. 2008), and older people with impaired function (Taraldsen et al. 2011), also observed an underestimation of step count, however, the estimated bias was not as large as the bias noted in this study. The percentage errors remained less than 1% in most studies. Although the participant groups are different from the current study, it is not clear if stroke and its characteristics alone could be the reason for this large variation, especially as only two of the 12 participants exhibited a typical hemiplegic gait pattern.

A further analysis, by comparing the data based on its placement on the affected and non-affected sides, was undertaken to identify any pattern of discrepancy. However, the findings did not change when the monitor was compared with video observation based on its placement on the affected side. The underestimation of the activPAL™ was further increased to 77.7 steps (PE 22.4%) when the monitor on the non-affected side was considered. However, the reason for this could not be determined.

Only the study by Taraldsen et al. (2011) had considered the validity of the monitor based on the affected side and non-affected side. Their results also demonstrated underestimation of number of steps by the activPAL™. However, their estimated bias was much lower, at 5.69 and 4.36 for the affected and non-affected sides respectively.

Nevertheless, their PE for the non-affected side was close to the error noted in the current study, at 26.91%. Interestingly, the percentage error for this measurement on the affected side was very high at 53.40% in the Taraldsen et al. (2011) study, compared to the PE of 19.1% noted in the current study. Taraldsen et al. (2011) had included both stroke and hip fracture patients in their study and this different patient group could have contributed to the higher error on the affected side. As noted earlier, only two participants demonstrated a typical hemiplegic gait pattern in the current study.

Gait speed was considered as a possible contributing factor for the underestimation of the step count by the activPAL™. The gait speed of participants in the current study was 0.7 ± 1.4 m/s, which was much lower than the normal gait speed of older adults (1.54 ± 0.14m/s) in the study of Grant et al. (2008). Kanoun (2009) identified that the underestimation of steps by the activPAL™ increased as the gait speed decreased. Taraldsen et al. (2011) put forth a similar argument that the low gait speed of their participants accounted for the high underestimation of steps. It should be noted, however, that the gait speed of the participants in the above study was much lower, at 0.47m/s (Taraldsen et al. 2011). Interestingly, the authors inspected the raw data and found that the steps were registered by the accelerometers. They indicated that the algorithm used in the automatic software procedure may not be effective for slow stepping and recommended a more appropriate algorithm for older adults with impaired function who may walk slowly. Although the researcher did not analyse the raw data in this instance, the above arguments could be made for the current study.

It should be noted that a definition of what counts as a 'step' for the activPAL™ has not been established, and therefore the researcher's interpretation of a step could be different to the step count, as calculated by the accelerometer's software. However, most of the published studies did not define a 'step', and hence comparisons were not possible to enable exploration of whether the definition used in this study influenced the results.

In this study, dragging or shuffling of the feet was not considered to be a step. It was difficult to record the number of steps taken from the video recordings when the participant was turning around. The turning movements involved both feet shuffling and a 'step'. Extra care was taken to count only the steps taken as per the definition. It should be noted that if the feet shuffling was included as steps, the estimated error would have further increased. The excellent intra-observer reliability for video observation strengthens the criterion measure, however, the subjectivity of this measure should not be ignored. The difficulty of identifying steps when turning around was also experienced by Taraldsen et al. (2011), which led them to exclude tasks that involved turning. This could not be done for the current study as, due to space restrictions, all walking activities involved a turning phase. None of the other studies reported any difficulty in identifying the number of steps taken.

Another secondary analysis of the data based on the number of steps taken during each walking activity revealed that the highest discrepancy occurred during the TUG test. The PE was very high, at 37.4%. In three participants, the activPAL™ did not record any steps for the entire four trials of the TUG test. In a study of young healthy participants, the authors observed that the activPAL™ did not register any step count during the TUG test and that the entire activity was recorded as sitting (Choo et al. 2011). In the current study, the activity was identified in some instances as sitting and in others as standing. Taralsden et al. (2011) included the TUG test as one of the tasks in their study, however, the authors did not provide any specific details regarding the step count for this task. No other study evaluated the TUG test in this context. The mean time taken to complete the TUG test was 16 ± 7.67 seconds. This short duration test involved a sit-to-stand transition, walking for three metres, turning around, walking back for three metres, turning around, and a stand-to-sit transition. The activPAL™ operates in epochs of 15 seconds, and since the TUG test is of a very short duration, the activPAL™ may have failed to record this activity and the number of steps. Analysing raw data may provide an

explanation as to whether the activity was recognised but not presented in the processed output.

Davies (2010), in his unpublished M.Sc. dissertation with pre-school children, explained that the default settings of the activPAL™ software for the minimum sitting time and minimum upright time were both changed to one second to ensure that all activities and posture transitions were recorded, irrespective of their duration. The default setting for both domains is ten seconds and this was not altered for the current study, in order to enable comparison of the findings with other published studies. Since the results of the current study showed discrepancies for activities of shorter duration, the default setting of the software was changed (to one second) and a sample of the data (three recordings) from this study was re-processed. The reprocessed data identified steps taken during the TUG test. This suggests that the activPAL™ may record all the activities, but the processed output is based on default settings which may not be an accurate indication of actual activity. Reprocessing of all the data from the current study was not conducted as none of the published studies have mentioned the change of default settings, and comparison of findings would not have been possible. Moreover, the manufacturer's rationale for setting ten seconds as the default setting is not known, and therefore altering the default settings could not be justified. However, the possibility of changing the default settings could tie in with the argument made by Taralsden et al. (2011) for modifying the algorithm for specific populations in future studies.

6.6.3.2.2. Reliability

The inter-device and test-retest reliability of the activPAL™ for the number of steps taken were perfect (Table 6.3 and Table 6.4). Previous studies in healthy young populations have demonstrated similar perfect to substantial ICCs when establishing inter-device and test-retest reliability for this measurement (Ryan et al. 2006, Choo et al. 2011, Tsavourelou et al. 2009, Dahlgren et al. 2010, Busse ME 2009). Although the relative reliability was perfect, the SEM was high, which reduces the absolute reliability

(25.5 for inter-device reliability and 34.6 for test-retest reliability) for this measure. However, none of the above mentioned studies used SEM, and therefore no comparisons could be made with the existing literature. One participant had a step count which was around thrice the step count of the other participants. This led to a higher SD (152.6 for inter-device reliability and 156.3 for test-retest reliability) for the average number of steps and therefore a larger SEM. If these data were to be removed, the SEMs would be reduced to 4.5 for inter-device reliability and 18.0 for test-retest reliability, increasing the reliability property of the activPAL™ for the number of steps.

6.6.3.3. Time spent in various positions

6.6.3.3.1. Concurrent validity

The time spent in sitting and upright positions recorded by the activPAL™ was in agreement with video observation, demonstrated by a estimated bias close to zero (0.1 ± 0.5 minutes for time spent in sitting and 0.2 ± 0.6 minutes for time spent upright) and narrow LOA. The low PE strengthened this finding. The findings were similar when the activPAL™ was considered based on its placement on the affected and non-affected side. Although other studies used different statistical methods to evaluate concurrent validity, the conclusion that activPAL™ recorded the time spent in sitting and upright accurately was supported (Grant et al. 2006, Taraldsen et al. 2011, Godfrey et al. 2007, Tsavourelou et al. 2009). Only one study found an underestimation of sitting time by 7.7 minutes. However, the direct observation method used in this study was different and hence comparison may not be valid (Kozey-Keadle et al. 2011).

The time spent in standing and stepping recorded by the activPAL™ had a large estimated bias, with the activPAL™ overestimating standing (-1.0 ± 0.6 minutes) and underestimating stepping (1.3 ± 0.5 minutes) in comparison with video observation. The PEs for these were also considerably higher (32.9% for time spent in standing and 27.2% for time spent in stepping). Wide LOA were also reported by Grant et al. (2006).

However, in their study, the activPAL™ underestimated standing time and overestimated walking time. Having no well defined cut-off point between standing and stepping could have contributed to this discrepancy between the activPAL™ and video observation. The researcher considered the start of stepping to be when the participant lifted his/her foot off the ground (initiated walking) on the instruction to start walking. The activPAL™ could have registered the change from standing to stepping slightly later. This argument fits in with the finding that the activPAL™ overestimated standing time and underestimated stepping time. Grant et al. (2006) discussed that if an activity/position is interrupted by a different short activity/position, then the activPAL™ does not recognise the interruption and processes it as one continuous activity. This could be the case in the current study as the TUG test lasted a very short duration. Therefore, the activPAL™ could have not processed the walking involved in the TUG test.

6.6.3.3.2. Reliability

For all positions (sitting, standing, stepping, and upright), the activPAL™ demonstrated excellent inter-device and test-retest reliability properties, with perfect ICCs and SEMs less than one (Table 6.3 and Table 6.4). Only two previous studies evaluated the inter-device reliability and the results were similar to those of the current study (Grant et al. 2006, Tsavourelou et al. 2009). No studies have considered the test-retest reliability properties of the activPAL™ and hence no comparisons could be made.

6.6.3.4. Number of transitions

6.6.3.4.1. Concurrent validity

The agreement between the activPAL™ and video observation for both sit-to-stand and stand-to-sit transitions was low, with large estimated bias, wide LOA, and high PE. In the study by Harris et al. (2006) with six participants with stroke, the authors identified a discrepancy of 2.3 counts (SD 5.1, 95% CI -7.7 to +12.2) between direct observation and

the activPAL™ for the number of sit-to-stand transitions. Although the discrepancy and the confidence intervals appeared to be high, the authors concluded that the activPAL™ was a useful tool for this measure. Since this was an abstract from a conference presentation, more details would be required to understand how the authors arrived at this conclusion. On the other hand, the findings of the current study were in contrast to the results of other studies, where the activPAL™ recognised all the transitions accurately (Grant et al. 2006, Taraldsen et al. 2011).

The processed output from the activPAL™ only provides the number of transitions, and not the timings at which these transitions occurred. Therefore, it was not possible to analyse which particular transitions were missed and if this was consistent for all participants. One possible explanation could be related to the short duration of the TUG test in relation to the standard measurement epoch of the device. If this test was recognised as sitting by the activPAL™, the transitions involved in the test (one sit-to-stand and one stand-to-sit for each TUG test), might have been missed. If this were the case, then there should have been overestimation of sitting time; however, that was not the case. Hence, it is unclear as to what contributed to the differences between the two measures for the number of transitions.

In order to find an explanation for these differences, the default settings for the minimum time in sitting and minimum time upright were changed from ten seconds to one second as suggested by Davies (2010), and a sample of the data (three recordings) was re-processed. Two recordings which showed the maximum discrepancy (participant 11 and 12 showing a discrepancy of six transitions) and one recording which showed the accurate finding (participant 1) were chosen for this. The reprocessed data showed a higher number of transitions than the initially processed data. This suggests that the activPAL™ may record all transitions, but the processed output is based on default settings and therefore, transitions occurring outwith the minimum sitting and upright time may not be identified. For reasons explained earlier (sub-section 6.6.3.2.1), all data

were not re-processed. The default settings of the activPAL™ were altered to two seconds in the study of Harris et al. (2006). Irrespective of this, the number of transitions recorded by the activPAL™ were not accurate in this study. Therefore, it is not clear if any other explanation could be provided for the variations noted for the number of transitions.

6.6.3.4.2. Reliability

Inter-device reliability of the activPAL™ for the number of transitions was excellent, however, test-retest reliability was moderate to substantial. The reliability properties of the activPAL™ for this measure have not been previously evaluated and hence no comparisons could be made.

6.6.4. **Strengths of the study**

Although the psychometric properties of the activPAL™ had been evaluated in various populations, this study was designed specifically to evaluate these properties in people who have had a stroke. Taralsden et al. (2011) had included stroke participants, however, it was a mixed population study and the results were not presented specifically for stroke.

This current study also examined validity and reliability for several additional measures of activPAL™, i.e. number of steps, time spent in various positions, and number of transitions. Moreover, to our knowledge, intra-observer reliability of video observation in this context has not been published previously.

6.6.5. **Study limitations**

Although the study had its strengths, there were several limitations too. Firstly, the sample size was small. Difficulties encountered in recruitment and time restrictions on

recruitment (as the study was being conducted as part of a PhD project with finite time lines) contributed to the small sample size. Inclusion of a second recruitment source to optimise recruitment did not yield the expected results. However, some previous activPAL™ validation studies have included similar numbers of participants (Grant et al. 2006, Ryan et al. 2008). Although the sample size was small, the mean gait speed and time taken to complete the TUG test are similar to the reference values for the stroke population (Wade et al. 1987, Severinsen et al. 2011, Andersson et al. 2006), thereby increasing the generalisability of the results.

Bland and Altman's LOA analysis was used in this study with a small sample. This small sample size could have widened the LOA, leading to a poor agreement between some measurements. However, the use of PE provided extent measure of the magnitude of error and the results were interpreted accordingly.

Additionally, Bland and Altman's LOA analysis is recommended for normally distributed data (Bland and Altman 1986). However, in this study, the data were negatively skewed and the use of Bland and Altman's LOA could be criticised. Nevertheless, all data points for all the measurements were within the 95% LOA, excluding one (section 6.5.8.5). Hence, it appears that the distribution of the data did not affect the results of the test.

Only one researcher was involved in the reduction of video observation data, introducing a possible subjective bias. This was reduced by the researcher observing the video recordings three times on different days. These data showed excellent reliability, thereby reducing the bias.

The activPAL™ has been designed for use over longer periods to measure free-living physical activity. Therefore, testing the monitor in a constrained environment for only around an hour may not be an accurate interpretation of free-living physical activity.

However, short duration activities may be common in this population and hence, validating the monitor for such use can be argued for.

6.6.6. **Recommendations for future research**

Studies with larger samples are required to confirm the findings of this study. The validity and reliability of this monitor over different gait speeds in this population requires analysis. The impact of adjusting the default settings or modifying the algorithm should be explored to improve the use of the activPAL™ in stroke. Exploration of the raw data may also enhance our understanding of the findings, which should be undertaken, if possible. Attempts should be made to validate the monitor in free-living conditions over longer periods of time.

6.7. **Conclusion**

A study was conducted in twelve stroke survivors with a mean age of 63.6 ± 13.6 years, with the aim of pilot testing the designed goal setting intervention, familiarising the researcher with the application of the selected outcome measures, and validating the activPAL™ activity monitor for use in people with stroke. The person-centred goal setting intervention piloted within the study required no changes. No difficulties were encountered with the application of any of the selected outcome measures. Therefore it was decided that the same procedure would be used for the goal setting intervention and the outcome measures for study four of this programme of work, which is presented as the next chapter of this thesis (chapter 7).

All participants were comfortable in wearing the activPAL™ activity monitor and since no data were lost, it was decided that the activPAL™ would be used to measure free-living physical activity for the next study. The results indicated that the monitor was a valid and reliable tool to measure time spent in sitting and upright. However, its

accuracy was reduced when the upright time was separated into time spent in standing and stepping. The accuracy of the monitor in identifying transitions was also questioned. The activPAL™ underestimated the number of steps taken and therefore this variable may not provide an accurate representation of a person's step count. In line with the findings of this study, it was decided that only the valid measures of the activPAL™ (i.e. time spent in sitting and upright) would be considered in the next study.

7. **STUDY FOUR: Feasibility and experiences of person-centred goal setting for exercise after stroke – mixed methods case studies.**

7.1. **Introduction**

Study four of this programme of work which was conduced with the aim of assessing the feasibility and exploring experiences of the person-centred goal setting designed in study two, is presented in this chapter. First the aims of the study are outlined. The study design used is justified next, followed by the study methods. The results of the study are then presented as individual case studies. This is followed by a discussion of the results and conclusions.

7.2. **Aims**

The aims of the study were to:

1. Examine the feasibility of the goal setting intervention for exercise after stroke described in chapter 5.

   Feasibility in this context included the following: recruitment from the exercise after stroke setting; setting/creating goals in this population; acceptability of the goal setting process by the participants; delivery of the goal setting intervention by the principal researcher (TS); adverse effects from the intervention; participants' compliance with the intervention and participants' compliance with the study (e.g. outcome measures)

2. Evaluate the participants' experiences of the person-centred goal setting intervention.

3. Analyse the changes observed in the selected outcome measures: time spent in sitting/lying (activPAL™), time spent upright (activPAL™), Canadian

Occupational Performance Measure (COPM), ten metre walk test (10MWT), Timed Up and Go (TUG) test, Stroke Impact Scale (SIS), Stroke Self-Efficacy Questionnaire (SSEQ).

Person-centred goal setting was expected to influence physical activity, and therefore standardised outcome measures measuring various aspects of this construct were chosen. In the current study, the changes in these outcome measures over the data collection points were analysed to explore their responsiveness, and any possible effects of the person-centred goal setting intervention.

The primary research questions were:

1. What is the feasibility of including a person-centred goal setting intervention within an exercise intervention for people with stroke?
2. What are the participants' experiences of being involved in the goal setting intervention?
3. What are the changes observed in the selected outcome measures (time spent in sitting/lying (activPAL™), time spent upright (activPAL™), COPM, 10MWT, TUG test, SIS, SSEQ) over the study duration?

7.3. **Study design and justification**

In order to answer the research questions, a mixed methods cohort study with ten participants was initially planned. However, this was not possible due to the issues faced with recruitment. The researcher took all possible measures to optimise recruitment, such as having a multiple recruitment strategy, extending the recruitment period, and improving the communication with the relevant personnel. In spite of these measures, recruitment was low, and therefore a mixed method multiple case study approach was adopted. A schematic representation of the study is presented as Figure 7.1. The recruitment issues are discussed in more detail in sections 7.5.1 and 7.6.1.1.

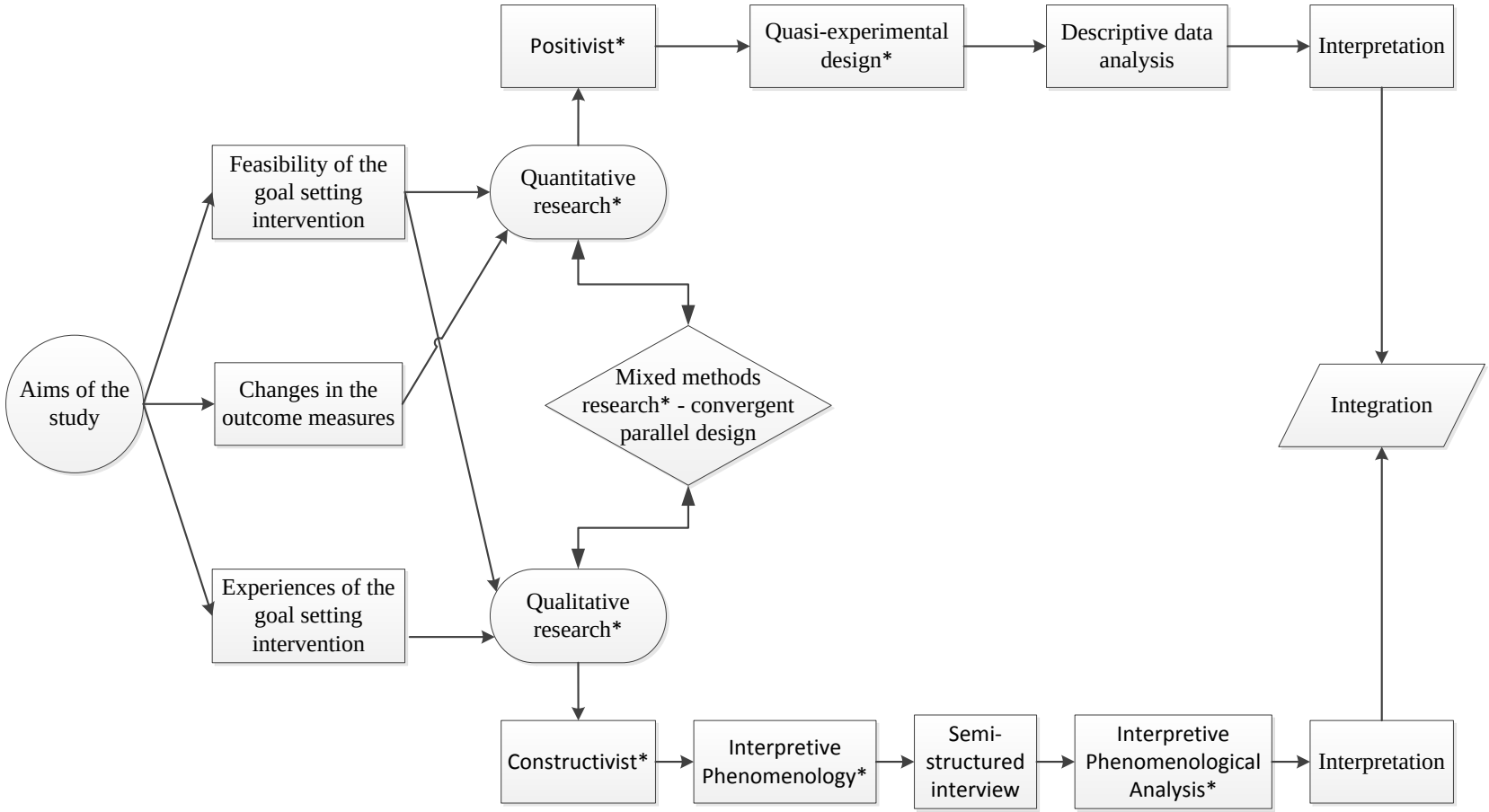

Figure 7.1: Schematic representation of the mixed method study design (study four)

Key: *- Terms are defined in the main text (section 7.3)

Mixed methods is a research design where both quantitative and qualitative data are collected and analysed, either within a single study, or a series of studies, and where each strand is guided by strong philosophical assumptions (Creswell and Plano Clark 2011). Creswell and Plano Clark (2011) explain that the central premise of this design is that both methods are being used in combination to provide a better understanding of the research problem in question than would be reached by each of the approaches being used alone (Creswell and Plano Clark 2011, Creswell 2014). In order to explore the feasibility issues, changes in the outcome measures, and participants' experiences of goal setting, a mixed methods study was deemed the most appropriate and hence was chosen for this study. The mixed methods approach has been one of the preferred research designs in recent years, where the aim of the study is to explore and evaluate a new complex intervention or service (Plotnikoff et al. 2010, Gannotti et al. 2013, De Joode et al. 2012, Hauken et al. 2013), thereby, further justifying the choice of this method for the current study.

Within the mixed methods research design, a convergent parallel design was adopted (Creswell 2014). In this design, quantitative and qualitative data are collected concurrently, with each strand given equal priority, and analysed separately. The results are then integrated to allow for comparisons and better understanding of the results from the individual strands. From this, an overall interpretation is developed (Creswell 2014). Accordingly, quantitative data were collected from the participants to evaluate the changes in the outcome measures, and qualitative data were collected from the same participants to explore their experiences. The data were then analysed separately and finally integrated to provide an overview of the feasibility issues of goal setting for exercise after stroke. The theoretical underpinnings for each strand are presented next.

7.3.1. **Quantitative research**

A quantitative research design was employed to evaluate the changes in the outcome measures selected for this study. Quantitative research is defined as, "an approach for

testing objective theories by examining the relationships between variables. These variables, in turn, can be measured, typically on instruments so that numbered data can be analysed using statistical procedures" (Creswell 2014, p.4). This research paradigm operates within positivist thinking, whereby truth is believed to be objective and that by careful research this objective truth and meaning can be attained (Crotty 2003).

Quantitative research can be of experimental, quasi-experimental, or non-experimental designs (Sim and Wright 2000). Quasi-experimental design is defined as a study where manipulation of variables is carried out without randomisation and with/without having a control group (Sim and Wright 2000). The current study used this design. Within a quasi-experimental design a multiple case study approach was adopted for this study.

7.3.2. **Qualitative research**

A qualitative research design was considered to be best suited for exploration of participants' experiences of the goal setting intervention. Qualitative research is defined as: "approaches which seek to uncover the thoughts, perceptions and feelings experienced by informant" (Minichiello et al. 1995, p.10 in Crotty 2003, p.5). Crotty (2003) outlines four elements of research, namely, epistemology, theoretical perspective, methodology and methods, that each inform the other. Appropriate alignment of these elements is emphasised to increase rigour in qualitative research (Whittemore et al. 2001). Further, it is recommended that an appropriate framework is identified and that collected data are analysed and interpreted within this framework (Grbich 1999).

Epistemology is "a way of understanding and explaining how we know what we know" (Crotty 2003, p.8). Although all participants were expected to receive the same goal setting intervention, it was assumed that each individual may experience this intervention differently and assign different meanings to the same intervention. This view of the world that the 'truth' has multiple meanings and is subjective to individual interpretation and the context of the current situation is located within the constructivist

paradigm (Crotty 2003, Grbich 1999) and the current study followed this line of thinking.

The individual and his/her experience of the goal setting intervention was planned to be the focus of this component of the study. Attempting to understand a phenomenon by focussing on the values and meanings provided by the individual is consistent with the interpretivist theoretical perspective (Crotty 2003).

In order to explore participants' views and experiences, a 'phenomenological' approach was believed to be best suited and this approach was adopted. Smith et al. (1997, p.69) explains that phenomenology is "concerned with an individual's perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself". In this approach, the researcher aims to ask specific questions about the experience and attempts to remove his or her own perspectives or experiences regarding the researched topic. The researcher seeks to understand the phenomenon being studied and interpret it only through the descriptions provided by the participants (Crotty 2003, Grbich 1999).

It was necessary to gather in-depth data pertaining to the individual's experiences in order to obtain a greater understanding of the potential impact of goal setting. Therefore, a semi-structured, one-to-one interview method of data collection was chosen for this component of the study.

7.4. **Methods**

7.4.1. **Ethical approval**

Ethical approval for this study was given by the South East Scotland Research Ethics Committee 01, and the study was also approved by the NHS Lothian Research and Development Department. The amendments that were related to the recruitment strategy

and follow-up period were also approved by both these committees. All the ethical approval documents can be found in Appendix 11.

7.4.2. **Recruitment**

Participants who were referred to the selected EaS service were recruited for this study between November 2011 and July 2012. Due to the recruitment issues faced during the recruitment phase of the previous study (study three, chapter 6), it was decided by the researcher and the team that a multiple recruitment strategy would be used.

The Physiotherapists of NHS who referred patients to the above EaS service introduced patients to the existence of the study, and asked whether they would be willing for their details to be given to the researcher who could then contact them regarding the study. For people who were referred to the EaS service through other professionals such as GPs and Stroke Nurses, the Exercise Instructor of the EaS service in charge of these referrals, introduced the study to the participants. They also asked whether the participants would be willing for their details to be given to the researcher. In both cases, if participants agreed, their contact details were passed on to the researcher, who then contacted the participant with the information sheet (Appendix 12). Once a participant agreed to participate, consent was obtained in writing during the first appointment by the researcher (Appendix 12). A flowchart of the recruitment process is presented as Figure 7.2.

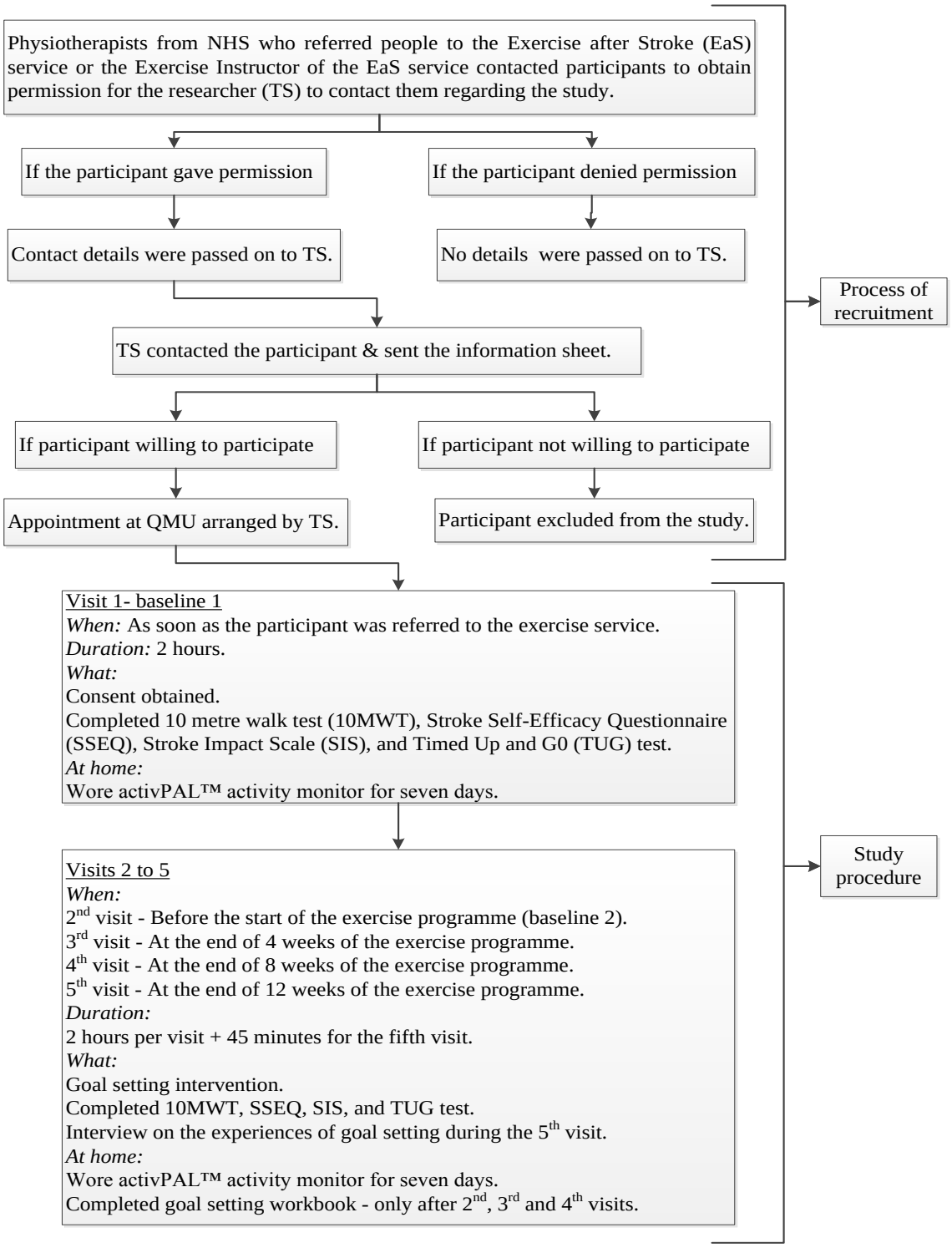

Figure 7.2: Flow chart of process of recruitment and study procedure (study four)

7.4.3. **Inclusion and exclusion criteria**

A participant was included in the study if he or she was referred to the circuit or one-to-one classes of the EaS service and was able to provide informed consent in writing. As explained in chapter 2, section 2.5, the selected EaS service is an exercise on referral scheme; hence participants must be referred through the appropriate health care professionals (i.e. stroke specialist health professional). The criteria for referring participants to the EaS service were that the participants must:

(i) have a confirmed diagnosis of Stroke (within the past ten years).
(ii) be motivated to participate in an exercise program.
(iii) be medically stable.
(iv) not put themselves or others at risk by presenting themselves under the influence of alcohol or drugs.
(v) be able to follow simple instructions by the most appropriate method (verbal, visual cues or written).

The details of the EaS service have been presented in chapter 2, section 2.5.

A participant was excluded from the study if he or she was:

(i) not able to provide informed consent.
(ii) not referred to the EaS service through the required process.
(iii) not referred to the one-to-one or circuit classes of the EaS service.

7.4.4. **Study duration**

Initially it was proposed that the duration of the study would be 28 weeks, with the participants having six visits during this period. However, delays in recruitment and the time constraints within the programme of work forced a change in the proposed plan. Therefore, the plan of having a three month follow-up period had to be dropped. Hence, the participants were involved in this study for 16 weeks and had five visits during this

period. Each visit lasted for a maximum of two hours, with breaks as requested by the participant.

The study duration and the number of visits were decided based on the following factors:

- Two baseline measurements (visits one and two)

In order to identify whether the participants were stable, or in a phase of spontaneous recovery, or deterioration, it was decided that two baseline measurements at least four weeks apart would be incorporated. A four-week gap between the first and second assessments was required for the assessments to be meaningful and for the participant to have a break from using the activity monitor. It was recognised that some participants may start the exercise class immediately on referral and therefore two baseline measurements may not be feasible. In such instances, it was decided by the team that a pragmatic approach would be followed, and only one baseline assessment would be conducted.

- Regular follow-up required for the goal setting intervention (visits two, three, and four)

In chapter 5 it was identified that regular follow-ups were required within a goal setting intervention. Therefore, follow-up visits were planned for every four to five weeks. The reasons for choosing this time frame have been explained in chapter 5, section 5.5.4.

- Reassessment period in the EaS service (visit five)

Within the EaS service, a participant is routinely reassessed after 12 weeks from entry to the class and is encouraged to move onto the next level of the class (from one-to-one, to circuit classes, to main-stream classes - refer to chapter 2, section 2.5 for details). Thus, 12 weeks from start of exercise class was chosen as the final assessment point.

In line with this, the participants had five visits over the 16 weeks of involvement in this study, as outlined below:

Visit one – baseline one on referral to the EaS service,

Visit two – baseline two just before the start of the exercise class,

Visit three – four weeks from the start of the exercise class,

Visit four – eight weeks from the start of the exercise class,

Visit five – 12 weeks from the start of the exercise class.

What happened during these visits is presented in detail later in this chapter in section 7.4.9.

7.4.5. **Study intervention**

The person-centred goal setting intervention developed in study two (chapter 5) and piloted in study three (chapter 6) served as the primary intervention of this study.

7.4.6. **Development of topic guide**

A semi-structured one-to-one interview was planned to capture the participant's views and experiences of the person-centred goal setting intervention. This was conducted during the participant's final visit for the study. A semi-structured topic guide which addressed all the components of the goal setting intervention was prepared for these interviews (Appendix 13). Accordingly, four key questions were developed and these focused on the participants' views of the goal setting process; their role in goal setting; their thoughts on the goal setting work book; and whether they would use goal setting in the future. Probing questions were also developed for each of the key questions to obtain in-depth discussion. The topic guide was reviewed and approved by the supervisory team.

7.4.7. **Researchers involved and their roles**

The researcher (TS) delivered the person-centred goal setting intervention throughout the study. The funding available for this programme of work did not allow for a blinded assessor to be recruited and therefore, the same researcher who delivered the intervention also conducted the assessments during the study period, inevitably

introducing bias in the quantitative data. Since the researcher was involved in delivering the goal setting intervention, it was not ideal for the same person to conduct the interview on the experiences of the intervention. Therefore, to reduce bias in the qualitative data, an experienced qualitative researcher (CB) from the supervisory team conducted all the interviews on the experiences of goal setting.

7.4.8. **Equipment**

The following equipment was used for this study:

(1) ActivPAL™ monitor (PAL Technologies Ltd 2010)
(2) ActivPAL™ key (PAL Technologies Ltd 2010)
(3) ActivPAL™ Docking station
(4) 3M Tegaderm® film
(5) Chairs with arm rest
(6) Digital voice recorder (Olympus WS-650S)
(7) Password protected laptop

7.4.9. **Testing protocol**

The study was conducted in the Gait Laboratory within QMU, Edinburgh. The flowchart in Figure 7.2 provides an outline of the study protocol. As mentioned earlier, the participants had either four or five visits (depending on the number of baseline measurements) for this study. What happened at each visit is discussed in the following sub-sections.

7.4.9.1. Visit one - baseline measurement one

At this visit, the aims and procedures of the study were explained and any questions were answered. Then, consent was obtained in writing. Demographic information (i.e. name, age and sex), along with other information such as time since stroke, affected

side, and co-morbidities was collected. If some details were missing, the researcher obtained consent to contact the participant's GP. In all cases, consent was obtained from the participants to inform their GP of their participation in the study.

During this visit, the participants first completed the 10MWT, followed by the completion of the SSEQ and the SIS, and finally the TUG test. This order of measurements ensured that the participants had sufficient sitting time in between walking tests. All participants followed the same order.

At the end of the visit, the participants were given an activPAL™ activity monitor to wear for seven days. The participants were instructed to wear the monitor on the anterior aspect of the thigh of their non-affected/stronger leg about a third of the way down between the hip and the knee, as per manufacturer's instructions. They were shown how to secure the activPAL™ in place using the 3M Tegaderm™ film, which allowed the participants to wear the monitor even during a shower. However, they were instructed to remove the monitor during swimming or bathing. They were also given an instruction sheet providing all the information, and a number to contact in case of difficulties. The participants were asked to return the monitor to the researcher after using it for seven days, in the stamped-addressed envelope provided.

7.4.9.2. Visit two - baseline measurement two

If this visit was the first visit for the participants, then the procedures presented under 'baseline measurement one' (section 7.4.9.1) were conducted first, before moving on to the following procedures.

During this visit, the participants were introduced to the person-centred goal setting intervention. Goals were discussed and set using this intervention, as explained in chapter 5, section 5.6. As part of the goal setting intervention, the goal setting workbook

was introduced and the agreed goals were documented. The goal setting discussions were audio-recorded using a digital voice recorder (Olympus WS-650S).

The participants then completed the 10MWT, the SSEQ, the SIS, and the TUG test. At the end of the visit, the participants were given an activPAL™ activity monitor to wear for seven days.

7.4.9.3. Visits three and four

During the third and fourth follow-up visits (4 and 8 weeks after the start of the exercise class, respectively), the goal setting intervention was applied in terms of discussing goal achievement/non-achievement, progression towards previously set goals, and setting of new goals. As in the previous visits, participants completed the 10MWT, the SSEQ, the SIS, and the TUG test, and were also asked to wear the activity monitor for seven days.

7.4.9.4. Visit five

During this visit, the goal setting intervention was applied in terms of only discussing goal achievement/non-achievement. As in the previous visits, the participants completed the 10MWT, the SSEQ, the SIS, and the TUG test, and were also asked to wear the activity monitor for seven days.

In addition, the participant's views and experiences of goal setting were gathered through a one-to-one semi-structured interview conducted by an experienced qualitative researcher (CB). The interviews were also conducted in the Gait Laboratory within QMU, Edinburgh. The interview took no longer than 45 minutes. With each participant's consent, the interviews were recorded using a digital voice recorder (Olympus WS-650S) to aid in analysis.

It was essential to ensure that the researcher (TS) did not influence the person conducting the interviews (CB). Therefore, only the demographic information of the participants was shared with CB. No information on the goals set by the participants or their involvement in goal setting was discussed. Once the interview was completed, a short meeting was held between the researchers, where CB provided a reflection on the interview and this was recorded in writing, to be used during analysis by the researcher (TS).

7.4.10. **Data protection and confidentiality**

At all times, the data collected were protected and confidentiality of the participant was maintained. At the start of the study, a participation number was assigned to each participant and this number was used throughout the study. The identifiable personal information collected from the participant was separated from the coded data and stored in a separate locked cabinet. Only the researcher had access to this data. The data files on the digital audio recorders were deleted once the data were stored in the researcher's password protected server for analysis. Care was taken not to present excessive personal information that would lead to identification of the individual by combining data.

7.4.11. **Variables of interest**

The number of participants approached regarding the study and the number who agreed to participate were documented. Reasons for non-interest were recorded, where possible. Any drop-outs and reasons for drop-out were also documented. All this information was used to determine the feasibility issues of recruitment and compliance (aim 1).

The information from the goal setting discussions and the goal setting workbook were used to address the feasibility of the person-centred goal setting intervention and its acceptability. The changes in the COPM performance and satisfaction scores, which were a part of the goal setting intervention, were used to address both aims 1 and 3. The

activPAL™ described in chapter 2 section2.9.1, was used to evaluate changes in the physical activity behaviour of the participants (aim 3). The participants were encouraged to wear the monitor for seven days. Wearing the monitor for an extended time period was expected to provide a more representative picture of the participant's physical activity behaviour. Once the participants returned the activPAL™ activity monitor, the data were downloaded to a password protected laptop through the PALdock charging station, using the appropriate software (version 6.4.1) (PAL Technologies Ltd 2012). The summary data were stored as a Microsoft Excel file (Microsoft Excel 2010). The data from the first day and the seventh day were excluded as in most cases the activPAL™ was not worn for the full day (during waking hours) during these days (i.e. the participant either started wearing the activity monitor only at mid-day, or removed the monitor for return before the end of the seventh day). Based on the findings of study three on the validity and reliability of the activPAL™ in people with stroke (chapter 6), only the time spent sitting and upright were considered in this study. Since the number of hours that the activPAL™ was worn each day differed between visits within participants as well as between participants, the time spent in sitting and upright were calculated as percentages rather than absolute numbers. This enabled comparison between visits within participants and between participants. Where possible, absolute values are presented.

The outcome measures discussed in chapter 6, namely, the 10MWT, the TUG test, the SIS, and the SSEQ, were used in this study to evaluate changes in participant's walking ability, balance, quality of life and levels of self-efficacy, respectively, over the study duration (aim 3). For the 10MWT, the average time taken to walk ten metres and the Standard Deviation (SD) was calculated from the four trials, for each visit. From this, the mean gait speed and the SD were also calculated. For the TUG test, the average time taken to complete the TUG test over four trials and the SD was calculated for each visit. From the completed SSEQ, a total score out of a possible 130 was obtained for each visit. From the completed SIS, aggregate scores (as explained in chapter2, section 2.9.5),

ranging from 0 to 100, were generated for each of the eight domains for each visit. The participant's rating of their recovery from stroke, which was part of the SIS, was also documented.

7.4.12. **Data analysis**

As discussed in section 7.3, a mixed methods study of convergent parallel design was followed in this study. Accordingly, the quantitative and qualitative data were analysed separately first, and then integrated to answer the research questions presented in section 7.2. Integration occurred at various levels, presented as Figure 7.3. The quantitative and qualitative results of each participant were integrated to explain the impact and experiences of goal setting for that particular individual and presented as individual case studies. The quantitative results from all the participants were integrated to compare the changes within each outcome measure. Similarly, the experiences of the individuals were compared to identify similarities and differences. Finally, the integrated quantitative and qualitative results from all the participants were merged to provide an overall picture of feasibility of goal setting in this setting of exercise after stroke. How the quantitative and qualitative data were analysed is presented in the sub-sections below.

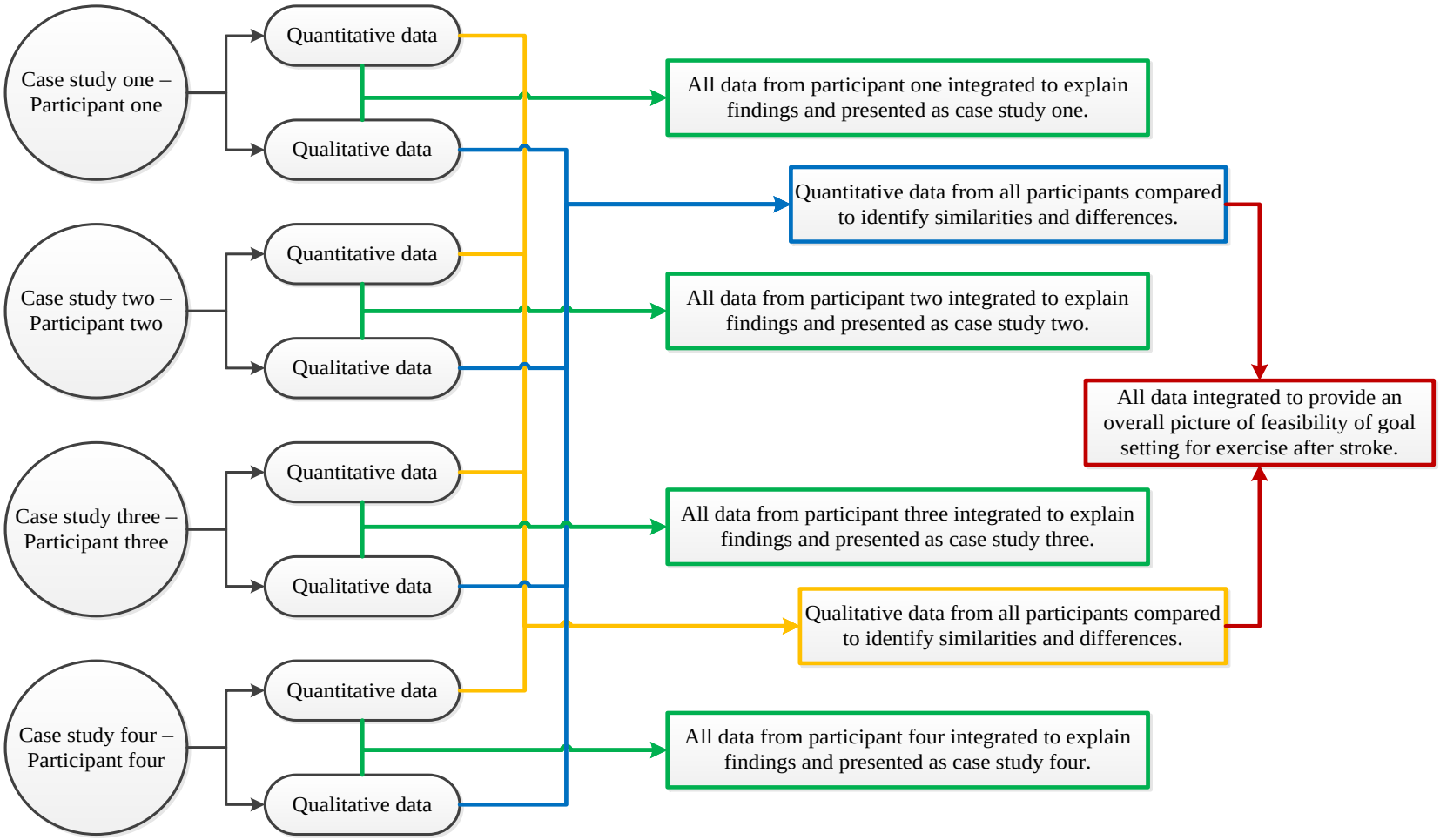

Figure 7.3: Schematic representation of data integration at various levels

7.4.12.1. Quantitative data analysis

Originally, a mixed methods cohort study was planned, and therefore, appropriate statistical tests had been planned to evaluate within group changes for all the outcome measures. However, a case study approach had to be taken due to recruitment issues. Multiple data collection points would have been required to perform regression analyses, however upon consideration it was decided that the burden of multiple assessments on participants would be unacceptable. Hence, with this small sample size and relatively few data collection points, it was inappropriate to do any statistical analysis. Therefore, only descriptive statistics including appropriate measures of central tendency and variation are used. Where possible, graphs and charts are used to illustrate the results. Errors bars are presented in the graphs when average values have been used, to demonstrate the variations within the data. Only one researcher (TS) was involved in this analysis. Advice was obtained from an experienced statistician within the University to inform the above decisions related to the analysis of quantitative data.

Since two baseline measurements were taken, a decision had to be made about whether one of the measurements, or the average of both measurements, was to be used as a single baseline value to enable comparisons with the end point. Researchers have suggested that this decision should be made based on clinical judgement or on previous studies (Chow and Liu 2004). Overall, they recommend that the average of multiple baseline measurements should be calculated to obtain a single baseline value (Chow and Liu 2004). Accordingly, when multiple baseline measurements were taken, the average baseline values were calculated for the 10MWT, the TUG test, the SIS, and the SSEQ for all the participants. It should be noted that the COPM was part of the goal setting intervention and was introduced only during the second baseline measurement, and did not require the average baseline calculation.

7.4.12.2. Qualitative data analysis

The interviews on the experiences of goal setting were transcribed verbatim. A summary of key statements for each interview was created and sent to the respective participants for verification. However, only one participant (participant one) responded and did not request any changes.

The transcribed data were analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al. 1999). The aim of IPA is to explore how people ascribe meaning to their experiences of a given phenomenon, in a particular context (Palmer et al. 2010). This approach was in line with the aims of the study and hence chosen for this study. In IPA, the researcher attempts to interpret and explain the participant's experiences by engaging in an analytic process (Smith et al. 1997). The systematic process outlined by Smith et al. (1999) [i.e. identifying similar ideas, creating themes, exploring the possible relationships between the themes as evident from the text, developing theory to explain the experiences] was followed.

The data analysis process is presented as Figure 7.4. The researcher read each transcript a number of times in order to understand the discussion. While reading, initial ideas from the text were noted in one margin, including either a summary of statements, or associations, or a preliminary interpretation. The next step was to identify emerging sub-themes from the initial ideas and these were coded for reference purposes. Connections between the sub-themes were then explored to create themes. Each theme was defined and coded for reference purposes. Connections between the themes were also explored. The themes and connections were re-checked against the transcript to ensure accurate reflection of the data. The analysis of a text unit from the interview of participant one is presented in Table 7.1 as an example to show the different steps followed.

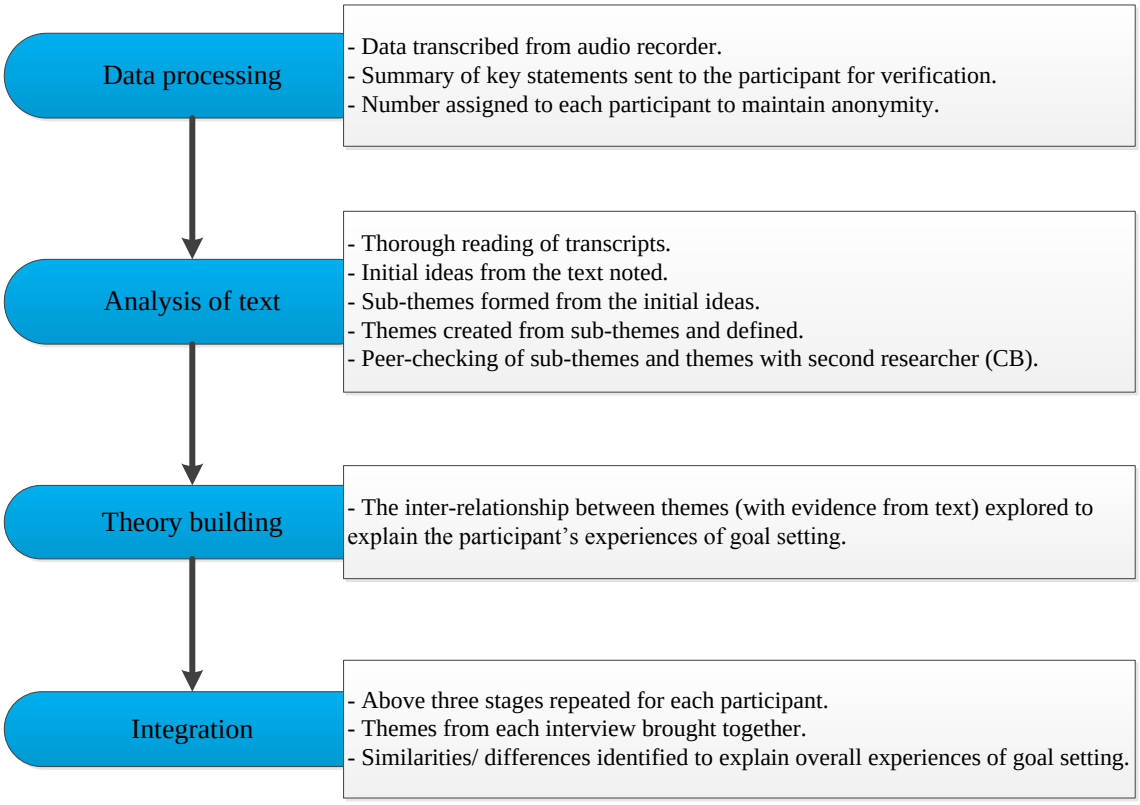

Figure 7.4: Data analysis process (study four)

The researcher (TS) first analysed one interview (participant 1) using the process described above. Since this researcher was new to qualitative research, the researcher (CB) who conducted the interviews reviewed the developed themes and sub-themes and was in agreement with the theme labels and definitions. This cross-checking enhanced the rigour of the study. The researcher (TS) then analysed the other interviews in a similar manner, keeping notes on the decisions made at each stage and the justifications for these as part of an audit trail, to ensure transparency of the process.

The themes from each interview were then grouped and explored further to identify similarities and differences between individuals regarding their experiences of goal setting.

Table 7.1: Illustration of qualitative data analysis (study four)

Text	Initial ideas	Sub-themes	Themes	Connections
[45]**Interviewer:** Do you think it [goal setting intervention] had any impact on your life?	Not sure of impact of goal setting intervention.	Value of goal setting	Attitudes towards goal setting	In this text unit, The participant connected his attitude towards goal setting (i.e. the lack of impact) to his familiarity with goal setting (i.e. would have set goals anyways).
[46]**Participant one:** … I am not sure will be the answer to that because, obviously when you have had a stroke, I would have been setting goals anyway, … may be not in a formal way, but I would have certainly intended to go back [to the gym] to work on the strength of my left side, and try to maintain some fitness and … tie that with healthier diet as well.	Would have set goals irrespective of the study.	Familiarity with goal setting	Familiarity with goal setting	
	Formal method of goal setting.	Approaches to goal setting		
	Goals – improve, strength on left side, improve fitness, healthy diet.	Awareness/ ownership of goals	Perceptions of goal setting	

7.4.13. **Rigour**

Rigour in quantitative research is usually denoted by validity and reliability (Sim and Wright 2000). Several measures were taken to improve the rigour of the quantitative strand. All the outcome measures used in this study, excluding the activPAL™, had sound psychometric properties established in the target population (refer to chapter 2 section 2.9 for details). Since the activPAL™ activity monitor had not been validated in the stroke population prior to this study, a pilot study was conducted (chapter 6) and only the measurements from the activPAL™ that were concluded to be valid and reliable were used in this study. One researcher (TS) conducted all the assessments, ensuring consistency and avoiding inter-rater variance. The researcher familiarised herself with the standardised protocols of all the outcome measures in the pilot study (chapter 6), thereby reducing error.

The use of the terms validity and reliability in qualitative research has been debated (Whittemore et al. 2001, Pope et al. 2002, Kidd and Parshall 2000). Kidd and Parshall (2000) explain that terms used to characterise reproducibility relate to reliability, while the terms used to describe the generalisability of the findings relate to validity. However, different researchers use different sets of terms to describe rigour (Whittemore et al. 2001).

The McMaster critical review form version 2.0, along with the section on trustworthiness from version 1.0 (Letts et al. 2007a, Law et al. 2002) was used to evaluate the qualitative studies included in the systematic review presented in chapter 4. This form had several criteria for rigour such as, triangulation, member checking, credibility, transferability, dependability and confirmability. Clear definitions were also provided for these criteria. Therefore, these terms were used in the current study as 'rigour' criteria for the qualitative strand. All attempts were made to ensure that these criteria for rigour were met to ensure quality of this study. The criteria, their definitions, and the actions taken to ensure the criteria were met are outlined in Table 7.2.

Table 7.2: 'Rigour' criteria and actions taken to ensure rigour for the qualitative part of study four

Criterion	**Definition** (Letts et al. 2007b)	**Action taken to ensure criterion was met**
Triangulation	Using multiple sources and perspectives to reduce the chance of systematic bias.	A second researcher (CB) was involved to check the data analysis process.
Member checking	Checking the findings with the participants	Key statements were summarised within a week of the interview and sent to all the participants for verification. Only one participant responded and was in agreement with the statements.
Credibility	"True" picture of the phenomenon by clear descriptions and recognisable interpretations of the participants' experiences.	A reflective approach was adopted by keeping a note of the principal researcher's (TS) preconceptions and the interviewer's (CB) reflections. The actions undertaken to ensure triangulation and member checking were also related to credibility.
Transferability	Relates to whether the findings can be transferred to other situations.	Participants and the settings were described clearly and in detail to make valid conclusions on the generalisability of the results.
Dependability	Relates to the consistency between the data and the findings.	An audit trail was maintained as evidence of the decisions made throughout the study. Peer review during the data analysis stage reduced individual bias.
Confirmability	Involves the strategies used to limit bias in the research.	Reflective journal, participant verification, peer review, and audit trail were undertaken.

7.5. **Results**

The recruitment and sample characteristics of the whole group are presented first, followed by the description of results of individual participants as case studies. Within the case studies, the results are outlined in the following order: description of goal setting discussions and self-report of goal achievement; information from the goal setting workbook on barriers and motivators to goal setting; changes in the COPM performance and satisfaction scores; changes in the activity monitoring data; and changes in the other outcome measures (i.e.) 10MWT, TUG test, SSEQ, and SIS. The individual's experiences of goal setting are then presented based on the findings from the interview. Feasibility of the person-centred goal setting intervention for the individual is then explored through integration of findings. Following this, the group analyses are presented for both the quantitative and qualitative data to provide an overall synthesis of feasibility, and experiences of goal setting. The raw data for all the above outcome measures and the transcripts of the interview for all the participants are attached as an electronic appendix (CD-ROM).

7.5.1. **Recruitment**

The plan was to recruit a minimum of ten participants for this study. This was identified as a feasible number by the EaS service authorities during the initial planning, and was appropriate to answer the research questions presented in section 7.2. However, recruitment to the study was low.

Eight potential participants were approached by the researcher, of which five agreed to participate in the study (recruitment of 62.5%). All these eight potential participants were referred by the Physiotherapists of the local NHS. They confirmed that no potential participant was missed, and that no potential participant declined referral to the study. On the other hand, no participants were referred from the EaS service over the entire recruitment period of nine months. On communication with the EaS service authorities,

it became evident that referral to the service was lower than expected and that this was impacting negatively on recruitment to this study. However, the exact number of referrals, the number approached for the study, and reasons for non-interest were not shared due to data protection issues. To overcome this problem, the recruitment period was extended by another two months (June and July 2012). However, this did not yield the expected results. Due to the time restrictions on the project, the recruitment period could not be extended any further and was stopped in July 2012.

Of the eight participants contacted by the researcher, five participants agreed to participate (a recruitment of 62.5%) and were recruited for the study. One person refused participation citing lack of interest in exercise as a reason, while the other two participants did not give a reason for refusing participation. Of the five recruited participants, one participant could not be contacted after the first visit and hence had to be considered a drop-out. Data from the remaining four participants were analysed and are presented here.

7.5.2. **Sample Characteristics**

All the participants recruited to this study were referred by Physiotherapists involved in a community stroke service. This is a stroke specialist community based rehabilitation service for stroke survivors, delivered in joint partnership between the local NHS and the City Council. All four participants were males, with a mean age of 55.5 years (SD 9.2, range 44 – 66 years). Three participants had a diagnosis of right ischaemic stroke, while one participant had a left ischaemic stroke. The participants were, on average, 7.3 months post-stroke (SD of 2.6, range 5 – 11 months). All participants were right-handed.

7.5.3. **Case study one**

7.5.3.1. Case characteristics

Participant one was a 54 year-old male with left hemiparesis. He was six months post-stroke at the start of the study. He was on medication for high blood pressure and asthma. At the start of the study, he was in the process of returning to work and by the end of the study, he was working his usual pre-stroke part-time hours.

7.5.3.2. Study pathway

At the time of recruitment, the participant had been referred to the circuit session of the EaS service. However, the participant was confident and felt well enough to attend the mainstream classes of the EaS service and therefore, chose that route. As per the study protocol, the participant was involved in the study for 16 weeks and had five data collection points.

7.5.3.3. Description of results

7.5.3.3.1. Goal setting discussions

On discussing goals with this participant, it was evident that he had a clear vision of his long-term goals, which included: getting physically fitter, gaining strength on the affected side (left), healthy eating, and losing weight. When the focus shifted onto goals relating to physical activity, the participant identified that regular exercise was key to improving physical fitness and regaining strength, and therefore chose the following three specific goals:

(1) Two hours of walking each day.

(2) Three gym visits every week.

(3) Two games of golf every week.

Since the participant expected that these activities would be a part of the foreseeable future, he did not want to set a time frame for any of the above goals. He felt that his

first goal would benefit him in two ways: firstly, to improve his physical fitness and secondly, to fulfil his responsibility of taking his dogs out for a walk.

During the first four weeks after the goals were set (between second and third visits), the participant set himself short monthly and weekly goals. Accordingly, he started with one and a half hours of walking every day, one or two visits to the gym every week, and one or two games of golf every week. At the end of this four week period (during the third visit), the participant felt he was working well towards his goals. The participant was confident in his walking ability and therefore wanted to increase his walking goal to around three hours per day, rather than two hours. Pre-stroke, the participant had spent a similar amount of time walking and therefore, was keen to increase his time spent on this activity. However, he recognised that his long-term goal of visiting the gym three times a week was therefore now unrealistic in terms of the time available and hence decided to change the goal to 'gym visit two times each week'.

During his next visit (fourth visit), the participant discussed that he was happy with the set goals and did not want to alter them. When asked about the gym visits, the participant explained that he spent around 20 minutes in cardiovascular training and then concentrated on strength and resistance training using weights especially to improve strength on the affected side.

During his final visit, the participant stated that he had achieved all his goals and that he was feeling better physically. He also recognised that extreme exertion was difficult; however, he was motivated to keep working hard to overcome this. In terms of his recovery from stroke, he illustrated his perceived confidence by giving the example that he could carry a drink using his left hand without having to think or worry about spilling it.

In terms of scoring his goal achievement on a scale of 0 to 100 in the goal setting workbook every week over the study duration, the ratings ranged from 60 to 100, denoting a fairly high perception of goal achievement throughout the study period.

7.5.3.3.2. Self-report of barriers and motivators

The main barrier that this participant identified, both in the workbook and in the goal setting conversations with the researcher, was the lack of time to work towards some of the goals. Work issues and family commitments were seen as the reasons for the lack of time. The participant also often reported that the weather interfered with his goal-related activities, such as playing golf.

When questioned about what made him work towards his goals, he mentioned that the goals were related to his health (which he valued as highly important) and therefore, he wanted to achieve them to improve his health. This, he felt, made him put in more effort to find time to work towards his goals. He also tried to overcome some of the barriers, such as the weather, by choosing alternative activities at that time (e.g. going to the gym in the scheduled time rather than playing golf).

In the workbook, the participant commented ‘good’ and ‘motivated’ for the question on how he felt in relation to working towards his goals.

7.5.3.3.3. COPM performance and satisfaction scores

The COPM performance (COPM-P) and COPM satisfaction (COPM-S) scores demonstrated gradual increases over the visits. When the initial scores (during the second visit) and the final scores (during the final visit) were compared, the COPM-P scores and COPM-S scores improved by 2.7 and 3 points, respectively. A score change of 2 or more is recognised as a clinically significant change (Law et al. 2005). On

exploration of the changes in the scores of the individual goals, it was evident that the scores of all the goals had improved by 2 or more points (Table 7.3).

Table 7.3: COPM-P and COPM-S scores and changes - participant one

Goals set	COPM-P score		**Change in COPM-P score**	COPM-S score		**Change in COPM-S score**
	Pre-intervention (second visit)	Post-intervention (final visit)		Pre-intervention (second visit)	Post-intervention (final visit)	
Walking	8	10	**2**	7	10	**3**
Visiting gym	6	9	**3**	6	9	**3**
Playing golf	6	9	**3**	6	9	**3**
Overall score	6.7	9.3	**2.7**	6.3	9.3	**3**

7.5.3.3.4. Free living physical activity

The average time spent in sitting/lying and upright in a day over the data collection points is presented in Figure 7.5. It should be noted that percentage values are presented rather than the absolute values, since the number of hours the activPAL™ was worn each day differed between the visits (refer to section 7.4.11). As explained in section 7.4.12.1, the average baseline values have been calculated.

On average, the participant wore the activPAL™ for 16.2 ± 0.8 hours each day over five days over all the visits, of which 10 ± 0.9 hours were spent in sitting/lying, and the remaining 6.2 ± 0.3 hours spent upright. From Figure 7.5, it can be seen that the participant showed a gradual decrease in the time spent in sitting/lying and a gradual

increase in the time spent upright between baseline and the fourth visits, with a small (1.2%) reversal of change between the fourth and fifth visits. This change in time spent in various positions can be interpreted as a positive change in physical activity behaviour. Overall, there was an improvement of 6.2%, which, when converted into numbers of hours (based on the average number of hours the activPAL™ was worn by the participant), showed an average increase of one hour per day.

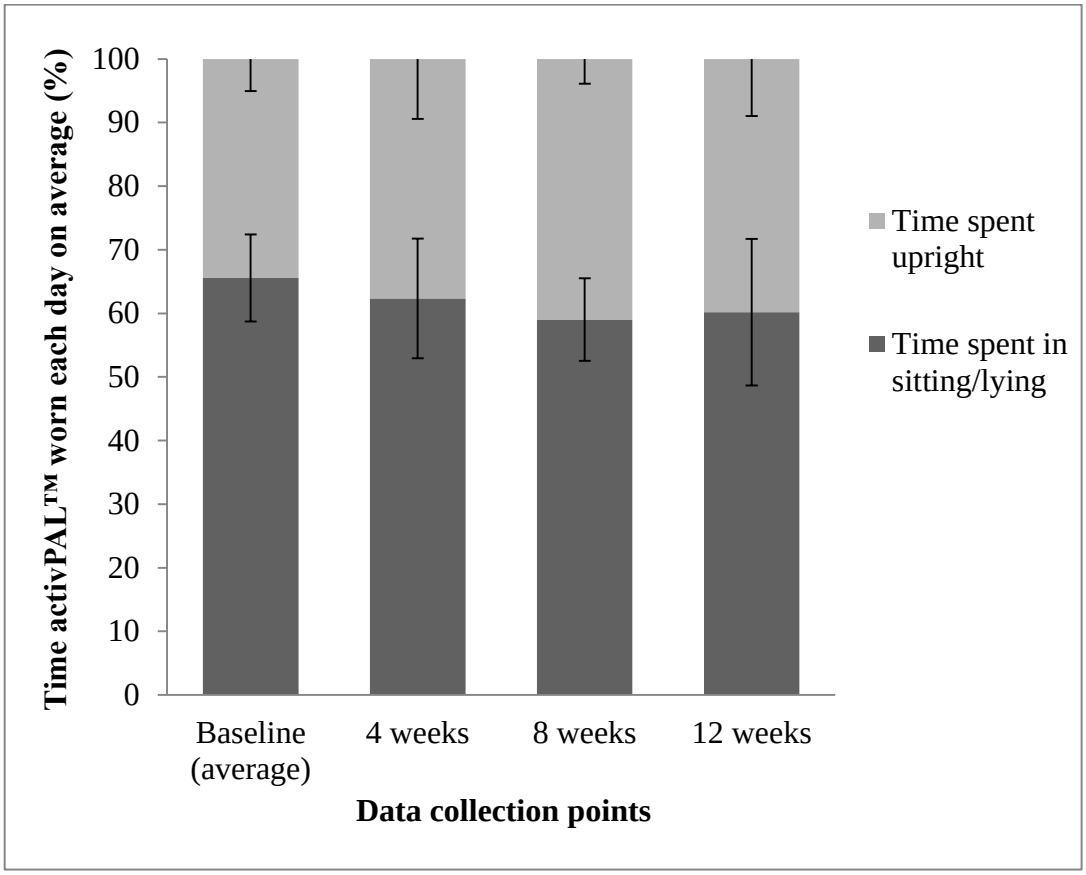

Figure 7.5: Average time spent in a day in sitting/lying and upright by participant one

7.5.3.3.5. Ten metre walk test

The mean gait speed of the participant at baseline was 1.04 m/s. The participant's change in the walking time of the 10MWT is presented graphically as Figure 7.6. From

the graph, it is evident that the walking time decreased 1.2 seconds (13.3%), from an average of 9.6 ± 0.6 seconds to 8.4 ± 0.3 seconds. However, it must be noted that the decrease in the time over the visits was not linear.

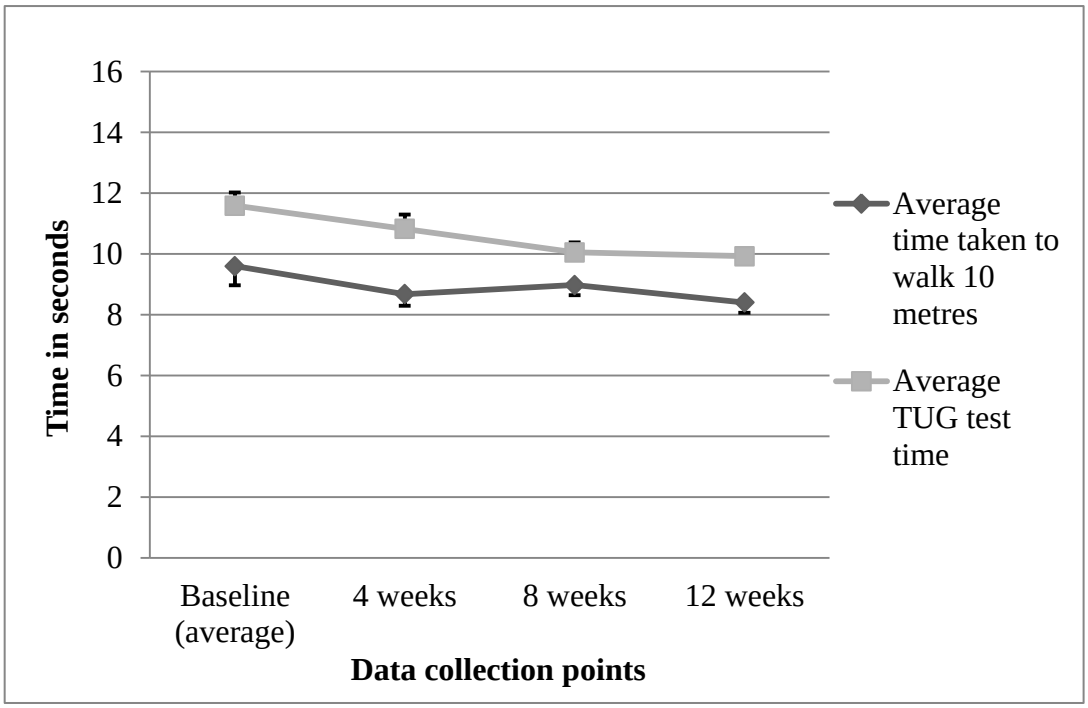

Figure 7.6: Average time taken to complete the 10MWT and the TUG test by participant one

7.5.3.3.6. Timed Up and Go test

The participant again showed improvement in the average time taken to complete the TUG test from baseline to the final visit (Figure 7.6), with the time taken decreasing from an average of 11.6 ± 0.4 seconds to 9.9 ± 0.1 seconds, a decrease of 1.7 seconds (15.5%).

7.5.3.3.7. Stroke Self-Efficacy Questionnaire

The SSEQ scores (maximum score 130) reflected a 3 point increase from baseline (125) to the end of the intervention (128) (Figure 7.7). As with the other measures, the change in score was not linear. Interestingly, the participant achieved the maximum score of 130 in the fourth visit.

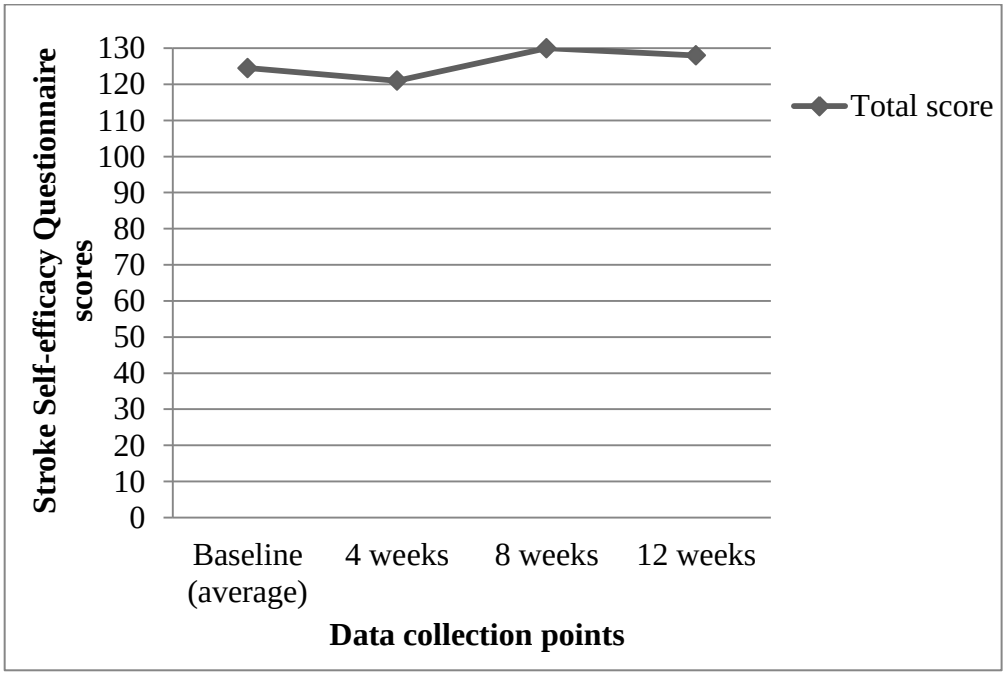

Figure 7.7: SSEQ scores for participant one

7.5.3.3.8. Stroke Impact Scale

Figure 7.8 provides a graphical representation of the changes in the aggregate scores of all the domains of the SIS and the scores on stroke recovery for this participant. All the domains showed a positive change overall from average baseline to end of intervention, denoting improvement in quality of life. Except for the domains of memory and emotion, the scores remained unchanged between the fourth and the final visits. For three domains, namely communication, mobility, and social participation, the participant

achieved the maximum score of 100 in the final visit, while he achieved the maximum score for emotion in the fourth visit.

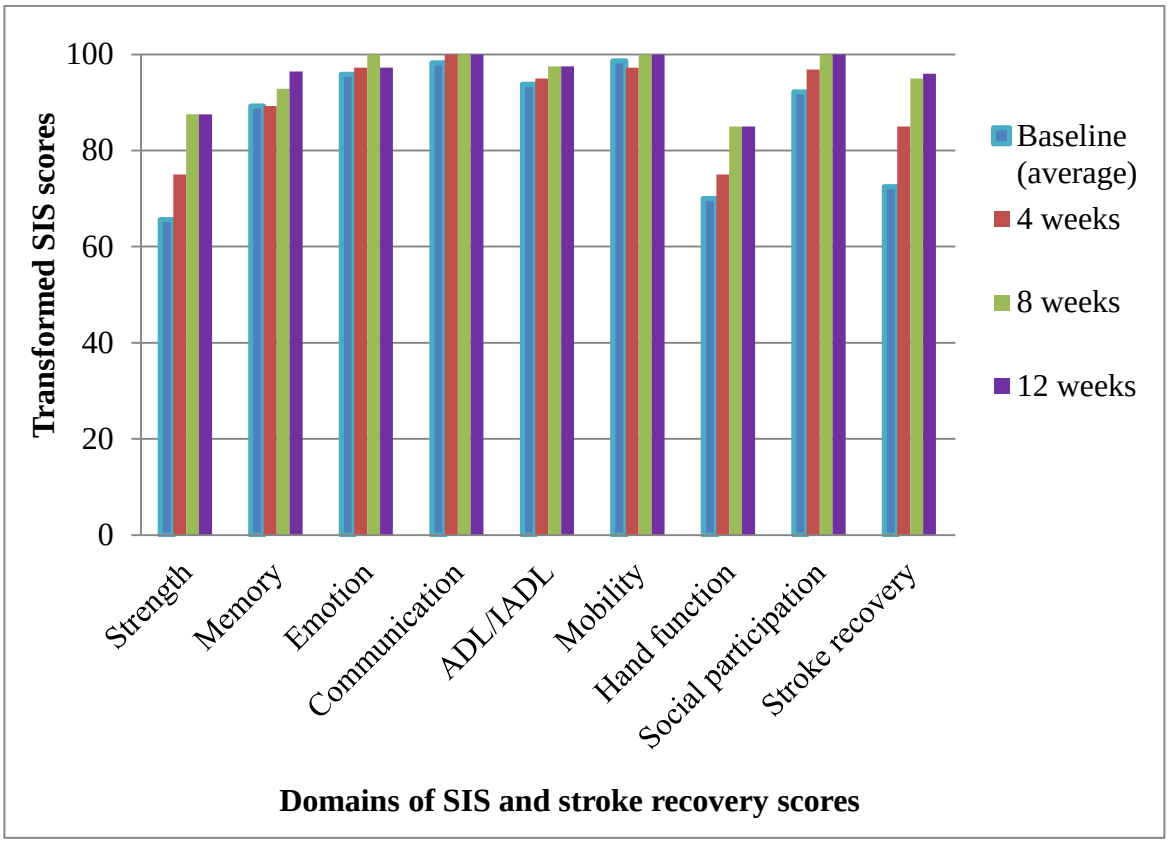

Figure 7.8: Transformed scores of the SIS for participant one

Key: SIS – Stroke Impact Scale; ADL – Activities of Daily Living; IADL – Instrumental Activities of Daily Living.

As for the question on stroke recovery, the participant scores improved gradually from an average baseline score of 72.5 to a score of 96 in the final visit, implying greater recovery.

7.5.3.4. Experiences of goal setting

On analysis of the interview of this participant, three themes were created. The first related to the participant's perception of goal setting, while the second addressed the attitudes of the participant towards goal setting. The participant's familiarity with goal setting appeared to link his perceptions of, and his attitudes toward goal setting, and hence was created as a linking theme (third theme). These themes, with the contributing sub-themes, are presented in the following sub-sections and illustrative quotations are used to demonstrate the evidence for the interpretative themes. Figure 7.9 provides a schematic representation of the themes and sub-themes.

Where possible, quotations are integrated within the text. If more than two quotes were selected to represent a sub-theme, then these quotes are presented as a table. Text unit numbers are provided as superscripts for all quotes to ensure transparency. In some cases, minor editing of extracts was made to improve clarity. These amendments are provided in square brackets. Omitted texts are denoted by ellipses.

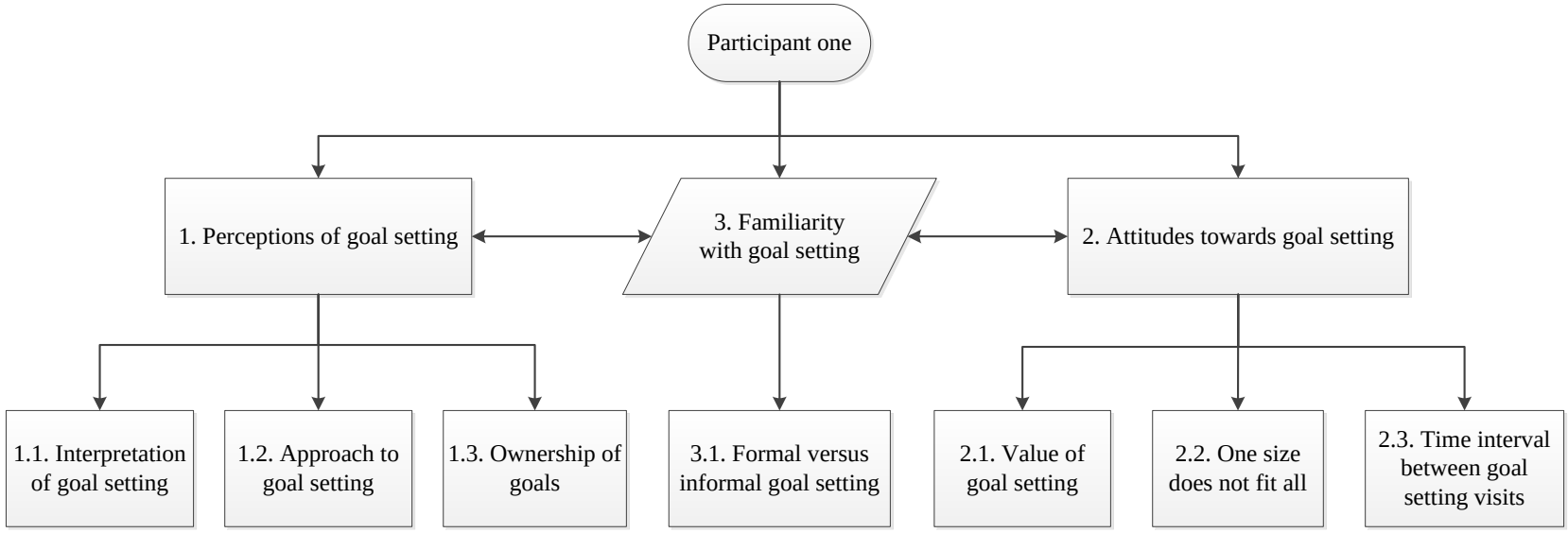

Figure 7.9: Theme structure of experiences – participant one

7.5.3.4.1. Perceptions of goal setting

Perception was defined as, "the way in which something is regarded, understood, or interpreted" by the Oxford English dictionary (Oxford University Press 2013). Based on this definition, three sub-themes were categorised within the theme of perceptions of goal setting. The sub-themes were the participant's interpretation of goal setting, his approach to goal setting and his ownership of the goals, discussed next.

Interpretation of goal setting

The participant expressed his understanding of the term 'goal setting' by using specific terminology such as "setting targets[8]", "logging things in a book[8]", and "chatting to somebody [the researcher] about it[8]".

Approach to goal setting

The participant had a clear vision of what his goals were going to be. In addition, he was also aware of the barriers he might encounter while working towards his goals and therefore emphasised "being realistic" when planning goals. This "cautious but realistic" approach is evident in the three quotes presented in Table 7.4.

Table 7.4: Illustrative quotes demonstrating the approach to goal setting adopted by participant one

[10]"… set aside time, trying [not] to get too ambitious, because we [participant and researcher] were talking of progressing, set goals higher. But the only thing I would say is you just got to watch because life gets in the way, you have got things to do. So I think you have got to be realistic in terms of time you can set aside."

[12]"I have been quite clear in setting my goals. Regular walks with my dogs, two games of golf a week on average, and I go to the gym twice a week. I think it would be quite easy to start to move it to three and then all of a sudden, I am not heading on with my goals. So then it turn[s] you down a bit."
[42]"I think I have been quite clear in terms of my goals. I never raised the bar too high. It was fairly achievable and so I have been cautious but realistic."

Ownership of goals

The participant expressed that he had complete ownership of the goals he set by stating, "I had a very clear part in that [setting goals]. In terms of making goals, I was the person who done that. I choose what I would like to do.[18]" He was also able to differentiate his role from the researcher's role in the goal setting process by explaining, "I was guided and everything else but I sensed that it was me. I was not set tasks by the researcher; I kind of never felt that … it was very much my way.[20]"

7.5.3.4.2. Attitudes towards goal setting

Attitude is defined as "a settled way of thinking or feeling about something" (Oxford University Press 2013). This theme was created to group the participant's attitudes towards the various aspects of the goal setting process. The three sub-themes that contributed to this theme are discussed in the following sub-sections.

Value of goal setting

The participant described the process of goal setting and the discussions on goal achievement or non-achievement as "worthwhile[22]". However, in many instances the participant appeared to have a 'non-negative attitude' rather than a 'positive attitude', as shown in the three quotes in Table 7.5.

Table 7.5: Illustrative quotes demonstrating the non-negative attitude of participant one

[10]"I don't think it's [goal setting] a bad thing at all. I think it helps."
[22]"I am just [used to doing] … things off the cuff, and … I don't think there was any harm in actually sitting down and creating goals. It's a bit more regimented than I am … used to. But I think it's been worthwhile because I got a clear understanding on what my goals are, and … so, even if I do not achieve them or exceed them at times, I still know what my baseline is in terms of … where I want to go."
[44]"I think it [discussion on goal achievement] was helpful. It certainly was not demotivating. It was helpful to do that."

When asked whether he felt goal-setting had impacted on his life, the participant answered "I am not sure[46]". However, he was able to recollect how the goal setting had made him more aware of fitness and physical activity and how that was reflected in his day-to-day life, by stating "depending on my mood…, I used to stroll about, whereas now, I am much more conscious about walking proper[ly] at a reasonable pace, and I am thinking the fitness aspect, and not just walking the dogs[38]".

One size does not fit all

Although the participant found the goal setting process "helpful[44]", he had certain criticisms regarding the goal setting workbook, as he found it "repetitive[26]" and "not tailor-made[50]" for him. However, he felt this was because he "did not have a severe kind of stroke, [but] a very mild stroke[28]" and that his "long-term goals … were really almost my short-term goals as well[28]". Further, he recognised that the workbook could benefit "people who were going to have to climb a ladder[32]". This understanding and reflection brought to the forefront the individuality of goal setting, hence the sub-theme 'one size does not fit all'.

Time interval between goal setting visits

On being asked his thoughts on the timings involved in the study (i.e. the four to five week interval between visits for follow-up on goal setting), the participant answered, "I think it was adequate … I do not feel like it was prolonged and I do not feel like [it was] rushed in any way either[24]". In addition he was able to understand and appreciate the rationale behind these timings, as illustrated below:

> [40]"I think if you close that gap, it will be harder for people … like myself … [or] for people back at work. It might be more of a chore, if you close that gap. If you left it too long, it would be like you would forget to [do] things. … Five weeks is reasonable. It would be picky to go either way."

7.5.3.4.3. Familiarity with goal setting

The participant was familiar with the concept of goal setting and had set goals in his life before. The familiarity and understanding of goal setting appeared to influence both his perceptions and attitudes towards goal setting and hence was considered a linking theme. In many instances, he referred to the goal setting method used in this study as "formal[4]", while his own method of goal setting was more "self-command[ed][6]". In addition, he was able to point out the differences between these two methods, as evident in the quote below:

> [7]**Interviewer:** So how do you describe formal?
>
> [8]**Participant one:** Well, logging things in a book etc., chatting to somebody about it, I never even had done that. So, before if I was … setting targets, to get out three times a week …, then it would be … just me saying to myself in doing it. I never wrote it down or spoke to anybody about it.

He did appreciate the benefits of this formal method of goal setting and considered it "worthwhile[22]". The participant's familiarity and its influence on his attitude towards goal setting were demonstrated clearly in the quote below:

[45]**Interviewer:** Do you think it had any impact on your life?

[46]**Participant one:** I am not sure, will be the answer to that because, obviously when you have had a stroke, I would have been setting goals anyway, … maybe not in a formal way. But I would have certainly intended to go back to [the gym to] work on the strength of my left side, and try to maintain some fitness and … tie that with healthier diet as well.

7.5.3.4.4. Summary of experiences of goal setting of participant one

Overall, participant one understood the process of goal setting, his roles within the process and took ownership of the goals and the goal setting process. This sound understanding was partially attributed to his familiarity with goal setting. Although the participant had several positive comments on the formal method of goal setting, criticisms were made regarding the repetitiveness of the goal setting workbook.

7.5.3.5. Feasibility of goal setting

In terms of the goals set, the participant identified that he had achieved all the goals and was satisfied with his performance. Positive changes, although small, were evident in all the outcome measures. Since all the achieved goals were related to physical activity, it was expected that the participant's overall physical activity would be improved by a bigger margin. However, the time spent upright as measured by the activPAL™ showed an improvement of only one hour per day. The participant, when talking about his experiences regarding goal setting, recollected that the quality of his walking had improved due to goal setting. This improvement in quality rather than quantity could have been the reason for high satisfaction with performance and therefore, not reflected in the objective outcome measure.

Another possible explanation could be that the participant may have reached pre-stroke physical activity levels, and hence was satisfied with his overall performance. The stroke

recovery scores within the SIS reached close to 100 (96%) at the end of the study, which could be an indication of this. It should also be noted that although the participant started attending the gym only after the baseline measurements, his level of participation in the other activities (walking and playing golf) before the start of the study was not known. If he was already participating, this may explain the smaller changes in all the measures. The fairly high baseline COPM-P (6-8) and COPM-S (6-7) scores could be an indication of this participation.

Overall, the goal setting intervention was applied to the participant without any difficulties. The participant was able to set goals and fully participate in the goal setting discussions. The participant also understood and valued the process. Further, no problems were encountered with the application of the selected outcome measures. Compliance with the intervention and the study were good. Therefore, it could be concluded that goal setting was a feasible intervention for participant one.

7.5.4. **Case study two**

7.5.4.1. Case characteristics

Participant two was a 44 year old male who had a right sided stroke 11 months prior to the first appointment and had a residual left hemiplegia. The participant used a walking stick on his right side for balance. He had worked full-time before the stroke, however, due to the stroke deficits he was not able to return to work. He also suffered from bronchial asthma and was on medication for this condition.

7.5.4.2. Study pathway

The participant was referred to the circuit session of the EaS service. Upon referral to the EaS service, he was also given appointments for assessment by the EaS service providers. However, the participant did not attend the exercise class during the course of his involvement in the current study. Since the goal setting process had already begun with the participant, he was not excluded from the study. Therefore, goals were set in terms of general physical activity. The follow-up appointments were scheduled according to the proposed time intervals in the study. The participant attended all the appointments and thus, had five visits in total.

7.5.4.3. Description of results

7.5.4.3.1. Goal setting discussions

Participant two had difficulty understanding research and the context of the study. Therefore, a lot of time was devoted to explaining the study aims and procedures. Similarly, the researcher took care that the concept of goal setting, the process of setting goals, and the participant's role in this were well-explained. Care was also taken to ensure that this information was repeated and reinforced in each visit.

Due to this difficulty, the participant did not come up with any goals initially. The participant also appeared to have the belief that he might not recover after this stroke and although he was referred to the EaS classes, he was not keen to participate in exercise classes. The researcher emphasised the role and the importance of physical activity in preventing recurrence of stroke. The researcher also had to stress that goals had to come from him and that the researcher would help him in identifying his problems and goals. After long discussions and probing questions, the participant identified certain problems and decided on the following long-term goals:

(1) To be able to walk without a walking stick in nine months
(2) To be able to walk to the shopping centre that was closest to his home in five minutes in six months.
(3) To be able to use the affected left arm in cooking and light weight-lifting in six months.
(4) To visit the gym once a week.

For the first month, short-term goals that could lead up to the long-term goals were decided. Accordingly, the participant wanted to try to walk without his walking stick within his home for short distances. He also aimed to walk to the shopping centre in 15 minutes. To improve his strength on the affected side, he aimed to visit the gym (as part of the EaS class) at least once a week.

During the next follow-up visit (third visit), the participant stated that he was trying to walk without his stick within his home and was getting confident in his walking ability. As for his goal of walking to the shopping centre, he mentioned that he had achieved his target time of 15 minutes on a few occasions and sometimes took around 20 minutes. The participant also stated that he was beginning to use his left arm in cooking; however, he was finding it difficult due to the reduced strength. He further recognised that this left arm function and strength may take time to recover and therefore decided to increase the time-frame on his third long-term goal to be achieved in nine months time

rather than six. He was happy to continue working towards these three goals for the next month. However, his fourth goal of attending the gym as part of the EaS class had not been attempted. He wanted to try to attend the gym during the following month.

At the following visit (fourth visit), the participant felt he was at the same stage with the use of his walking stick. During the four weeks between visits, the participant had noticed that he could walk for longer distances outdoors without getting breathless and tired, and was attempting to do more walking. His use of his upper limb in cooking remained the same. However, he still had not visited the gym. The researcher reinforced the importance of improving physical fitness to prevent a further stroke and encouraged him to be more active.

During the final visit, the participant recognised that the walking stick improved his confidence in walking and since he was concentrating on increasing the distance walked, he decided that his first long-term goal was no longer relevant or realistic. He stated that he was managing to use his affected left arm during cooking and was happy with the progress. He still had not visited the gym.

In terms of scoring his goal achievement in the goal setting workbook, the participant scored between 40 and 60 on a scale of 0 to 100, implying that the participant's perception of goal achievement was not high.

7.5.4.3.2. Self-report of barriers and motivators

Physical impairment due to the stroke noted in the goal setting workbook and in the goal setting discussions was the most frequent barrier that prevented the participant from working towards his goals. As for not visiting the gym, the distance to the gym and the lack of transportation were identified as reasons. Moreover, the participant was living on his own and was waiting for his family to arrive from another place. This issue came up several times during the goal setting conversations. The participant also mentioned a few

times that he would definitely go the gym when his family was with him. Therefore, lack of social support was interpreted as one of his barriers.

The participant did not identify any motivators. He felt that taking medication reduced his difficulties to a certain extent and that it helped him to improve his walking.

7.5.4.3.3. COPM performance and satisfaction scores

Although the participant had four goals in the beginning, by the final visit he had identified that his goal of being able to walk without his walking stick was no longer a goal and therefore, COPM scores were not calculated for this goal. The other goals were analysed in the usual manner. Both the COPM-P and COPM-S satisfaction scores showed an overall increase of 2.3 points between the initial measurement (during the second visit) and the final measurement for the three goals. However, it should be noted that not all the scores of the individual goals improved. The goal of visiting the gym was not achieved and therefore the COPM-P and COPM-S scores remained the same at 1 point from beginning to end and therefore the change score was 0 (Table 7.6). The increase in the overall scores was due to the reason that the other two goals (walking, use of left arm) showed great improvements (Table 7.6).

Table 7.6: COPM-P and COPM-S score and changes– participant two

Goals set	COPM-P score		**Change in COPM-P score**	COPM-S score		**Change in COPM-S score**
	Pre-intervention (second visit)	Post-intervention (final visit)		Pre-intervention (second visit)	Post-intervention (final visit)	
Walking to shopping centre	4	8	**4**	4	8	**4**
Use of left arm in cooking	3	6	**3**	3	6	**3**
Going to the gym	1	1	**0**	1	1	**0**
Overall scores	2.7	5	**2.3**	2.7	5	**2.3**

7.5.4.3.4. Free living physical activity

On average, the participant wore the activPAL™ for 16.4 ± 0.6 hours each day over five days over all the visits, of which 13.6 ± 1.1 hours were spent in sitting/lying, and the remaining 2.9 ± 0.8 hours spent upright. Figure 7.10 provides a graphical representation of the average time the participant spent in sitting/lying and upright in a day, across the data collection points. The time spent in sitting/lying increased between baseline and the final visit, while the reverse was apparent for the time spent upright. Therefore, the participant had a decrease in the performance of physical activity (8.2%) over the visits, which, when converted, provided a value of 1.3 hours. The decline was not gradual, with

the highest decline seen between the baseline measurement and the measurement at four weeks. However, the high SD, (as denoted by the error bars in the graph), particularly, for the time spent in sitting/lying should be considered when interpreting the results. The high SD was seen because of the difference in the time the activPAL™ was worn each day during each visit. Interestingly, this difference was reflected more in the time spent in lying/sitting than for the time spent upright. Therefore, it could be said that the participant spent approximately the same amount of time upright over the data collection period in each visit irrespective of the waking hours.

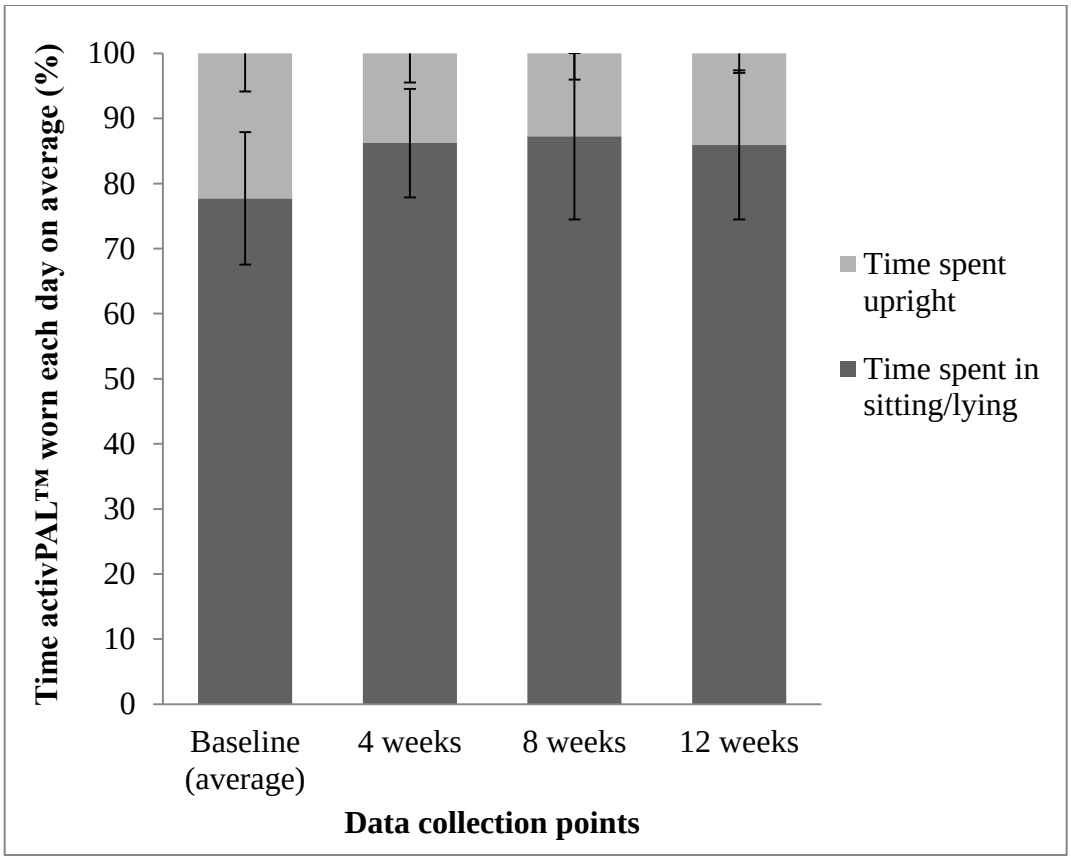

Figure 7.10: Average time spent in a day in sitting/lying and upright by participant two

7.5.4.3.6. Ten metre walk test

The mean gait speed of the participant at baseline was 0.47 m/s. Figure 7.11 shows that the walking time of the participant over a ten metre distance decreased from 21.1 ± 1.6 seconds at baseline to 19.9 ± 0.8 seconds at the final assessment, a decrease of 1.2 seconds (6%). The time taken to walk this distance decreased between baseline and the measurement at four weeks and then remained the same until the final visit at 12 weeks.

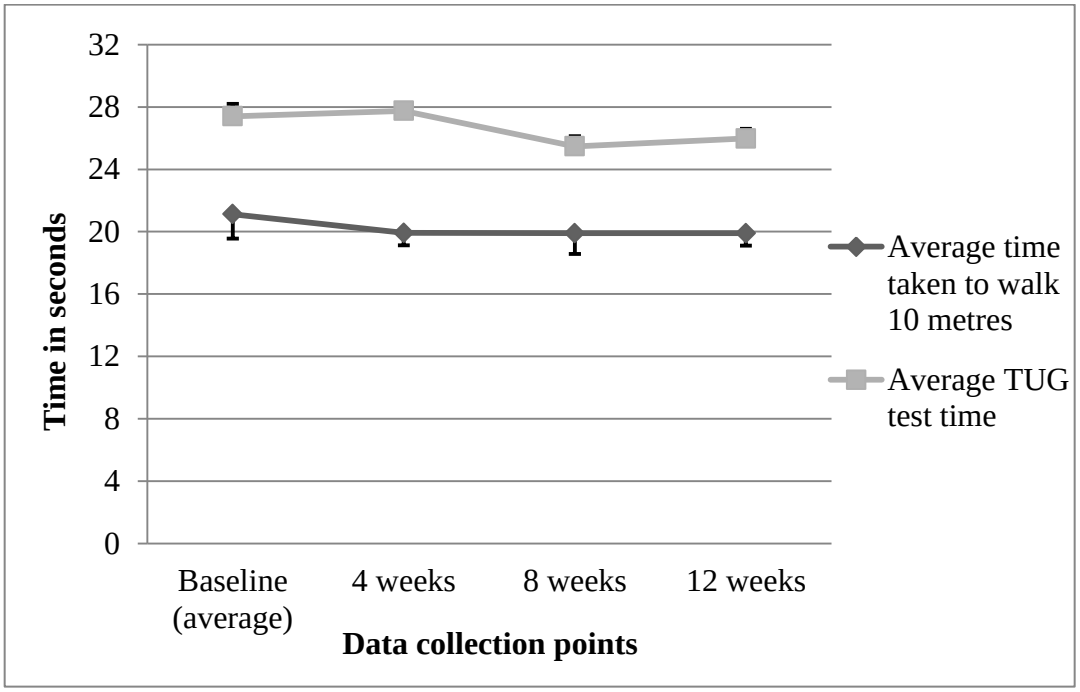

Figure 7.11: Average time taken to complete the 10MWT and the TUG test by participant two

7.5.4.3.7. Timed Up and Go test

The average time taken to complete the TUG test between the baseline and the final measurement at 12 weeks decreased by 1.4 seconds (Figure 7.11), from 27.4 ± 0.8 seconds to 26.0 ± 0.6 seconds, an improvement of 5.3%. However, the slightly high SD denoted by the error bars should be considered when interpreting the results of this test.

7.5.4.3.8. Stroke Self-Efficacy Questionnaire

For the SSEQ, the participant requested the researcher to read the questions and then answered them. The participant demonstrated an increase of 12 points on the SSEQ at the end of the intervention (97) when compared to the baseline measurement (85) (Figure 7.12). However, 97 was the maximum score that the participant obtained out of a possible 130, implying that the participant's self-efficacy was not high. Further, the participant's scores on individual items fluctuated widely, with no apparent pattern. For example, for the question 'how confident you are to use both your hands for eating your food', out of possible 10, the participant scored 7, 10, 0, and 5 at baseline, four weeks, eight weeks and 12 weeks respectively.

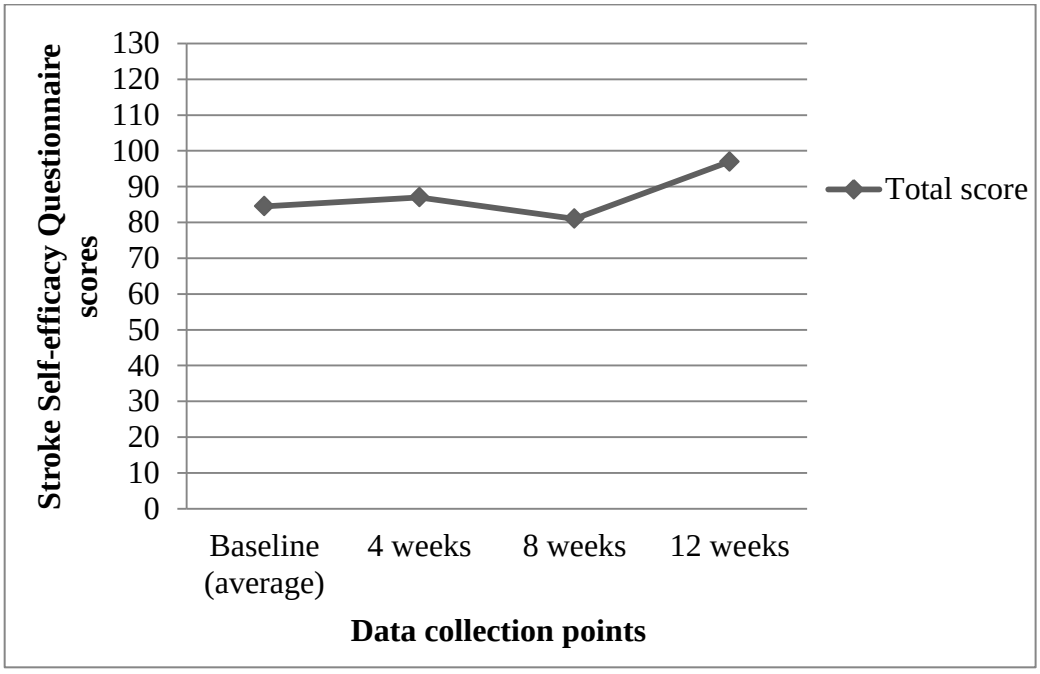

Figure 7.12: SSEQ scores for participant two

7.5.4.3.9. Stroke Impact Scale

As for the SSEQ, the participant requested the researcher to read the questions for the SIS and then answered them. Of the eight domains, four (strength, memory, emotion,

mobility) showed improvement between the average baseline measurement scores and the scores at final assessment, while three domains had lower scores (ADL/IADL, hand function, social participation), and one domain remained the same (communication) (Figure 7.13). Overall, the scores for each domain showed a high degree of fluctuation between the visits. Moreover, these changes were not consistent between domains. Only the communication domain score reached the maximum possible score of 100 (excluding the third visit), with the memory domain scores also very close to 100 (maximum of 96 during the fourth and fifth visits). The greatest improvement in scores was seen in the domain of emotion, where the participant's score soared up from 38.9 to 80.6. Strength and hand function domain scores remained low throughout, with the former scores ranging only between 5 and 25.

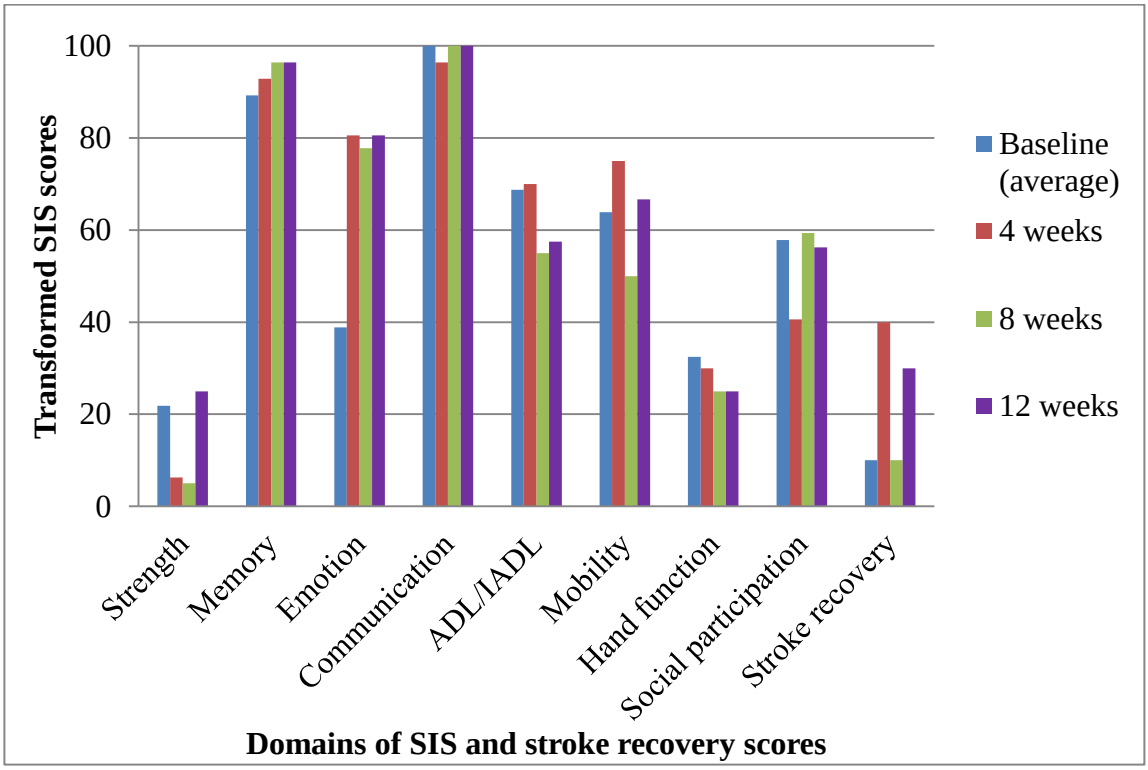

Figure 7.13: Transformed scores of the SIS for participant two

Key: SIS – Stroke Impact Scale; ADL – Activities of Daily Living; IADL – Instrumental Activities of Daily Living.

As for the question on stroke recovery, the participant scores improved from an average baseline score of 10 to a score of 30 in the final visit, implying recovery, although the change was not gradual. It should be noted that the recovery scores never rose higher than 40, highlighting the participant's low perceptions of recovery from stroke.

7.5.4.4. Experiences of goal setting

Three themes were created to explain the experiences of participant two (Figure 7.14). Two themes related to the participant's perceptions of, and attitudes towards goal setting. On exploring the data, it was identified that the personal characteristics of the participant influenced both the perceptions and the attitudes of the participant and hence was categorised as a third and linking theme. The themes and contributing sub-themes are discussed next with supporting illustrative text.

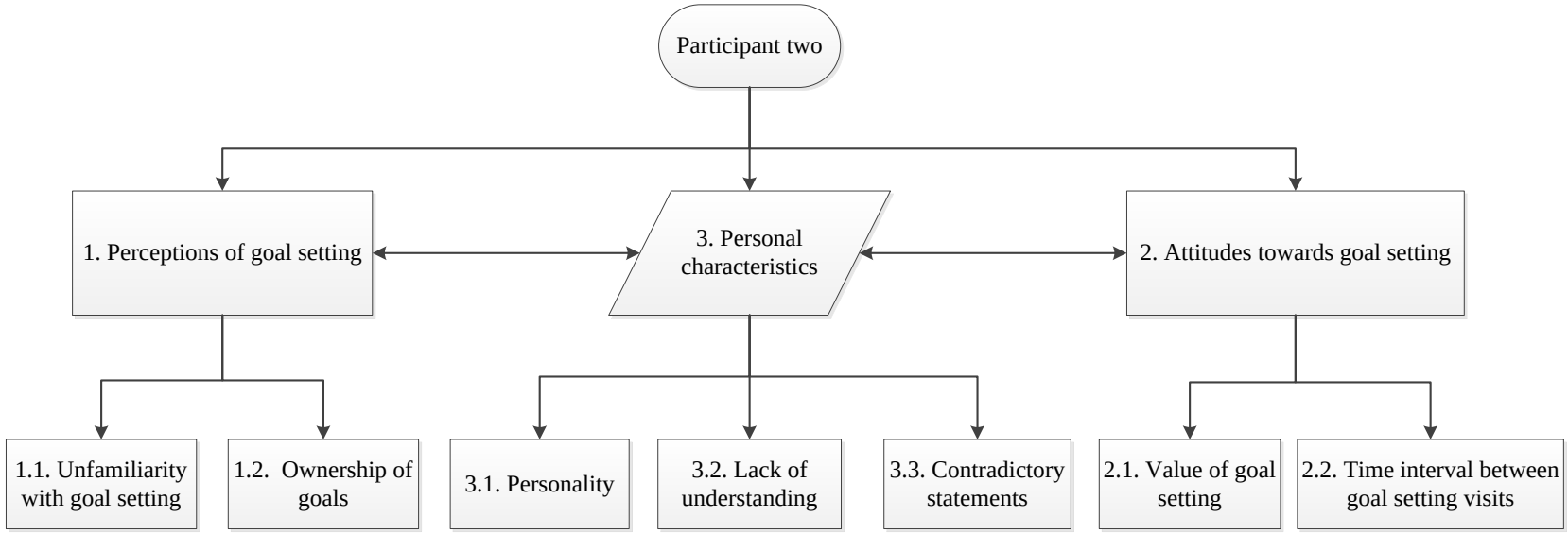

Figure 7.14: Theme structure of experiences – participant two

7.5.4.4.1. Perceptions of goal setting

Three sub-themes contributed to this theme and are discussed in the following sub-sections.

Unfamiliarity with goal setting

The participant answered "no[6]" when asked if he had ever set goals in his life. He considered the goal setting to be a new experience.

Ownership of goals

The participant was aware of the goals that were discussed during the study and mentioned them several times during the interviews, as seen below:

> [20]"To be able to walk better, to strengthen my arm … to work on the strength of my legs"

> [38]" To take my medication, to walk around, to go the shops, to visit my friends … cooking also"

However, when asked about who set the goals, he answered "She [the researcher] decided for me". He further added that "I was happy about it [the researcher's decision] because then I know I have to work towards these [and] because I never had any idea about this[26]". On further probing by the interviewer, he explained that the goals decided were the ones he liked and wanted, as evident in the below quote:

> [29]**Interviewer:** When you came to the conclusion that your goals were to strengthen your legs and strengthen your arms, were you happy with those goals?
>
> [30]**Participant two:** Yes.
>
> [31]**Interviewer:** Those were the things you wanted.
>
> [32]**Participant 2:** Yes to strengthen my legs and arms, that is what I liked about [it].

7.5.4.4.2. Attitudes towards goal setting

The attitudes of the participant were evident in the value placed on goal setting and in reflections on the timings involved in the goal setting process. The participant explained that he found the process of setting goals and discussing goal progress "useful[44]" and that he "liked[32]" it. The participant also felt that he had enough time to think about goals. He was "alright[54]" with the four to five week interval between goal setting sessions. However, as for the above theme, these responses were only obtained as 'yes' and 'no' answers on probing by the interviewer.

7.5.4.4.3. Personal characteristics

When the data were analysed to explore relationships, it became apparent from the responses that this participant preferred to be told what to do rather than deciding things on his own. This could explain why the participant felt that the goals were decided by the researcher rather than by him and only on probing was he able to identify that the goals set were those that he identified as problems.

On several occasions, the participant answered "I cannot explain that[12,68]". Lack of understanding, or ability to explain, could be possible reasons for this. However, the participant also made some contradictory statements (Table 7.7) which suggested lack of understanding to be an issue, rather than inability to explain.

Table 7.7: Illustration of contradictory statements made by participant two

[43]**Interviewer:** Was [the use of work book] a useful process or not? [44]**Participant two:** It was useful. Yes. [45]**Interviewer:** How did it affect what you did each day? [46]**Participant two:** It does not affect me. [47]**Interviewer:** So it did not really affect? [48]**Participant two:** No.
[69]**Interviewer:** Do you think you would like to continue to use this workbook at all? [70]**Participant two:** No, its ok. [71]**Interviewer:** So, probably not? [72]**Participant two:** Not. Yes. [73]**Interviewer:** If we are going to do goal setting with other people in the future, do you think we could make it any better? [74]**Participant two:** To have a book to achieve their goals, [75]**Interviewer:** Ok, so you feel it is quite good to do it with other people in the future? [76]**Participant two:** Yes.

7.5.4.4.4. Reflections of interviewer

Before the participant's experiences could be summarised, it was important to consider the reflections of the interviewer. The interviewer found the interview with this participant to be "extremely challenging" because the participant appeared not to understand the questions asked. Further, on more than one occasion the participant answered that he was not able to explain things. Therefore, the interviewer had to ask closed questions. Due to this, only 'yes' or 'no' responses were obtained. Where possible, the interviewer asked probing questions to obtain further explanations.

However, the participant was unable to provide these. Hence the interview was short, lasting only eight minutes.

7.5.4.4.5. Summary of experiences of goal setting of participant two

Overall, the participant provided very little account of his experiences regarding goal setting. Further, he did not appear to be able to reflect on his experiences to reach an opinion regarding certain concepts. His lack of understanding, both in relation to the questions asked, and the whole concept of goal setting, was apparent throughout.

7.5.4.5. Feasibility of goal setting

The participant had good compliance with the study. He attended all the sessions and was able to complete the goal setting workbook.

Goal setting was also possible with this participant. However, as explained earlier (section 7.5.4.3.1), the researcher had to probe for the participants' problems and facilitate him in deciding his own goals. Although maximum efforts were taken to ensure that the goals set were his own, the participant stated in the interview that the goals were set by the researcher. However, on probing, he was able to identify that the goals were the ones he wanted. This highlights that the participant did not understand the concept of person-centred goal setting.

The participant's low self-efficacy scores could partially explain the difficulties experienced in identifying and setting goals, and goal attainment. The participant's educational background was not known and therefore, it is not clear whether education was an underlying factor for the lack of understanding of concepts of goal setting. Barriers such as lack of social support could have also been a major contributing factor to lack of goal achievement (7.5.4.3.8). His low scores on the emotion domain of SIS at the beginning of the study could be an indication of the lack of social support. Further,

the participant's very low scores on the strength and hand function domain of the SIS, and his low scores regarding overall recovery from stroke, highlighted the greater physical impairment perceived by the participant. This could explain why the participant perceived physical impairments to be a barrier to goal achievement both in the goal setting workbook and in the discussions with the researcher. This, in turn, could have led to low self-efficacy, thereby creating a vicious cycle.

In spite of his low perceived physical fitness, he did not attend the EaS classes. The reasons explored in the above paragraph, such as low self-efficacy and lack of social support, could have influenced the decision of not attending the gym. During all the visits, the benefits of participating in exercise classes and improving physical fitness levels were emphasised by the researcher. It was also explained that his physical impairments may improve with regular participation in the classes. However, the participant did not attend the classes. Although the participant discussed that he was improving his walking distance and time, this was not evident from the activPAL™ which showed a decrease in physical activity. On the other hand, small percentage improvements were evident in the 10MWT and the TUG test, however the high SD observed within the measures reduces the significance of these small improvements. The researcher attempted to use the participant's perception of improvement (i.e. progression towards goal attainment) in guiding him towards the initiation of exercise uptake, without success, however. It is not known if participation in the EaS classes may have resulted in more significant improvements.

No difficulties were experienced in the use of selected outcome measures such as the 10MWT and TUG test. For the SIS and SSEQ, the researcher read out the questions and, in some cases, explained to the participant the meaning of the question. However, it is not clear if the participant understood all the questions of the SIS and SSEQ questionnaire. As mentioned in section 7.5.4.3.9, the scores for each domain of the SIS showed a high degree of fluctuation between the visits, with the changes not consistent

between domains. Similar fluctuations were also evident with the SSEQ (section 7.5.4.3.8). These could be reflections of the participant's lack of understanding.

On analysing all the data, it could be concluded that goal setting, although difficult, was a feasible intervention for participant two. However, the participant's understanding of goal setting has been questioned and this raises further questions on the overall use of goal setting for this participant. Since the participant did not participate in the EaS classes, any conclusions made relate to goal setting in relation to general physical activity, rather than to goal setting within EaS classes.

7.5.5. **Case study three**

Participant three was a 58 year old male who had a right sided stroke five months prior to the first appointment. The participant was not working at the time of the study, but had been involved in voluntary work pre-stroke.

7.5.5.1. Study pathway

The participant was referred to the circuit sessions of the EaS service. The participant had only one baseline assessment as he started the exercise class immediately after referral. During the third visit (8 weeks), the participant informed the researcher that he was in the process of relocating elsewhere, and therefore, requested a longer time interval for the final assessment. On discussion, it was decided to conduct this assessment at 16 weeks instead of 12 weeks. Due to the relocation, he was also unable to continue with the exercise classes, and therefore, the scheduled final assessment was considered as a follow-up assessment. The participant also had his interview on experiences during this final visit.

7.5.5.2. Description of results

7.5.5.2.1. Goal setting discussions

The participant identified the following long-term goals:

(1) To able to achieve maximum recovery (which he expected would be around 90% of pre-stroke status) in nine months.
(2) To be able to do all household work (both light and heavy) in six months.
(3) To be able to run in nine months.
(4) To be able to play golf in six months.
(5) To be able to play tennis in nine months.
(6) To start volunteering activity in four months.

He recognised that these goals were ambitious and that working toward these goals would be challenging, however, was motivated and willing to put in effort. The participant discussed that his reduced strength on the affected side and fatigue were the main difficulties and was determined to improve these. As a starting point on working towards the goals, the participant planned to undertake half an hour of swimming at least two days a week, walking for 400 metres every day and attending the circuit session of the EaS service once a week. Within the exercise session, he wanted to work on improving the strength of his affected side. He felt that undertaking these short-term goals would help to increase his stamina and decrease fatigue, thereby moving him closer to his long-term goals.

During his second visit, the participant stated that he was enjoying the circuit session. He felt that his balance was improving, which had helped him play a few games of golf. He discussed that he was managing to do a lot of the house work. He also felt that he was physically and psychologically low if he did not undertake physical activity. The participant was encouraged to continue with the exercise classes and work towards his other goals.

During his third visit (8 weeks), he discussed that he was not able to work effectively towards his goals due to personal life changes. He felt that his move to a new place may have an effect on his goal of maximum recovery in nine months; however, he was not able to set a time line for this goal at that point. Also, the goal of being involved in volunteering was no longer relevant.

During his follow-up visit, the participant discussed that exercise had taken a step back due to his move to a new location. Although he had not enrolled in a formal exercise programme, he was involved in walking and swimming. He expressed his disappointment in not being able to be more active. However, he was aware of the physical and mental benefits of physical activity and wanted to be as active as possible.

He still had the long-term goal of being able to run, which would also help him to play tennis.

In terms of scoring his goal achievement over the weeks on a scale of 0 to 100 in the goal setting workbook, the ratings ranged between 70 and 85, implying that the participant's perception of goal achievement was fairly high.

7.5.5.2.2. Self-report of barriers and motivators

In the goal setting discussion with the researcher and in the goal setting workbook, the participant indicated that his self-motivation was key in helping him achieve his goals. He also mentioned that his knowledge of physical activity benefits made him work harder towards his goals. He felt that fatigue was the main barrier to exercise; however, he also recognised that his fatigue levels would improve with more regular physical activity.

7.5.5.2.3. COPM performance and satisfaction scores

The goal of maximum recovery and volunteering were changed mid-way and therefore, COPM scores were not calculated for these. The other goals were analysed as per procedure. The COPM-P and COPM-S satisfaction scores showed an overall increase of 2.3 and 2 points respectively between the initial measurement (during the first visit) and the final measurement for the four goals (Table 7.8). As with participant two, not all goals showed improvement. The goals of running and playing tennis remained at the same level for both performance and satisfaction throughout the course of the study, and hence the change score was zero.

Table 7.8: COPM-P and COPM-S scores and changes - participant three

Goals set	COPM-P score		**Change in COPM-P score**	COPM-S score		**Change in COPM-S score**
	Pre-intervention (first visit)	Follow-up (final visit)		Pre-intervention (first visit)	Follow-up (final visit)	
Household work	3	8	**5**	5	8	**3**
Running	1	1	**0**	1	1	**0**
Playing tennis	1	1	**0**	1	1	**0**
Playing golf	1	5	**4**	1	6	**5**
Overall score	1.5	3.8	**2.3**	2	4	**2**

7.5.5.2.4. Free living physical activity

On average, the participant wore the activPAL™ for 14.8 ± 0.3 hours each day over five days over all the visits, of which 11.9 ± 0.6 hours were spent in sitting/lying, and the remaining 2.9 ± 0.7 hours spent upright. The average time spent in sitting/lying and upright in a day, over the data collection points, is presented in Figure 7.15. This demonstrates that the participant decreased the time spent in sitting/lying and increased the time spent upright between baseline and the final visit. This was viewed as an improvement in physical activity by 7.6% (i.e. a change of 1.1 hours). However, it should be noted that the change was not linear. The high SD, (as denoted by the error bars in the graph), particularly, for the time spent in sitting/lying should be considered when interpreting the results. This high SD was seen because of the difference in the time the activPAL™ was worn each day, and reflected more in the time spent in

lying/sitting than for the time spent upright. Therefore, it could be said that the participant spent approximately the same amount of time upright over the data collection period in each visit, irrespective of the waking hours.

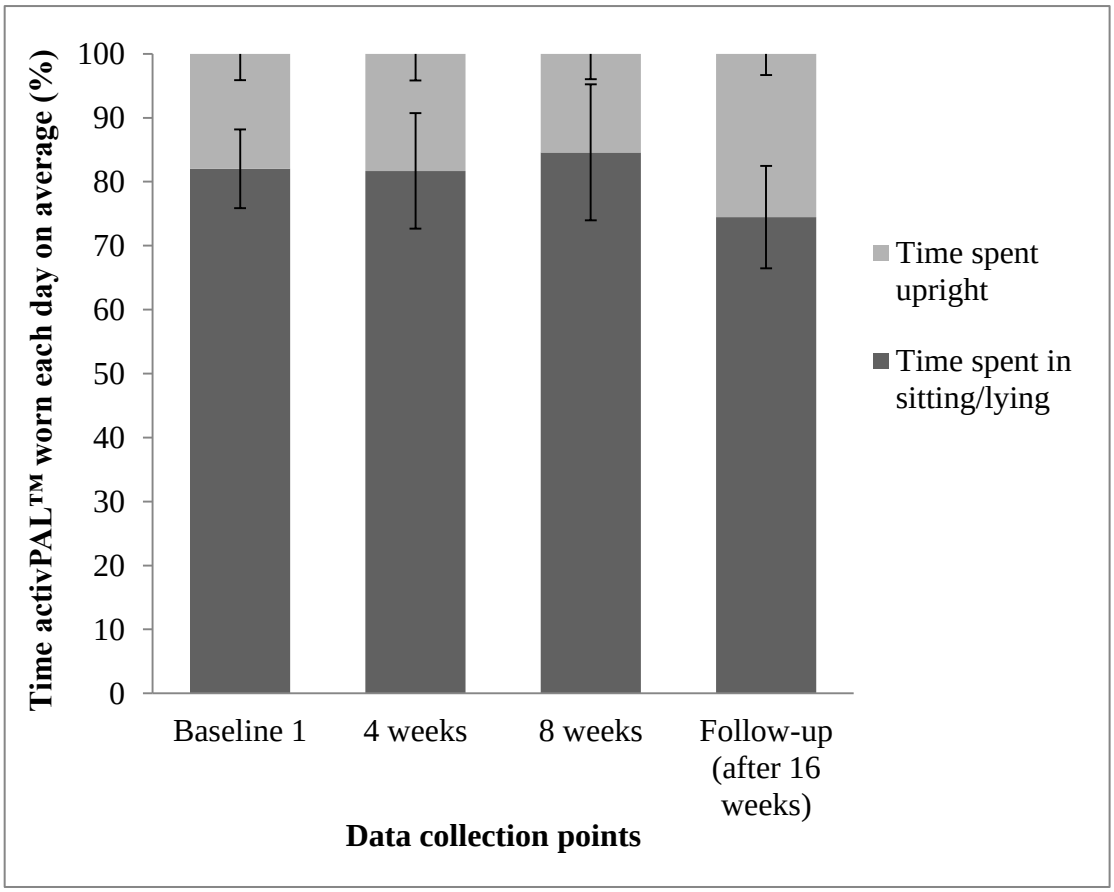

Figure 7.15: Average time spent in a day in sitting/lying and upright by participant three

7.5.5.2.6. Ten metre walk test

The participant had a mean gait speed of 0.74 m/s at baseline. The average time taken to walk ten metres gradually decreased from 13.6 ± 0.7 seconds in the first visit, to 8.1 ± 0.4 seconds in the final follow-up visit, a decrease of 5.5 seconds (50.7%) (Figure 7.16).

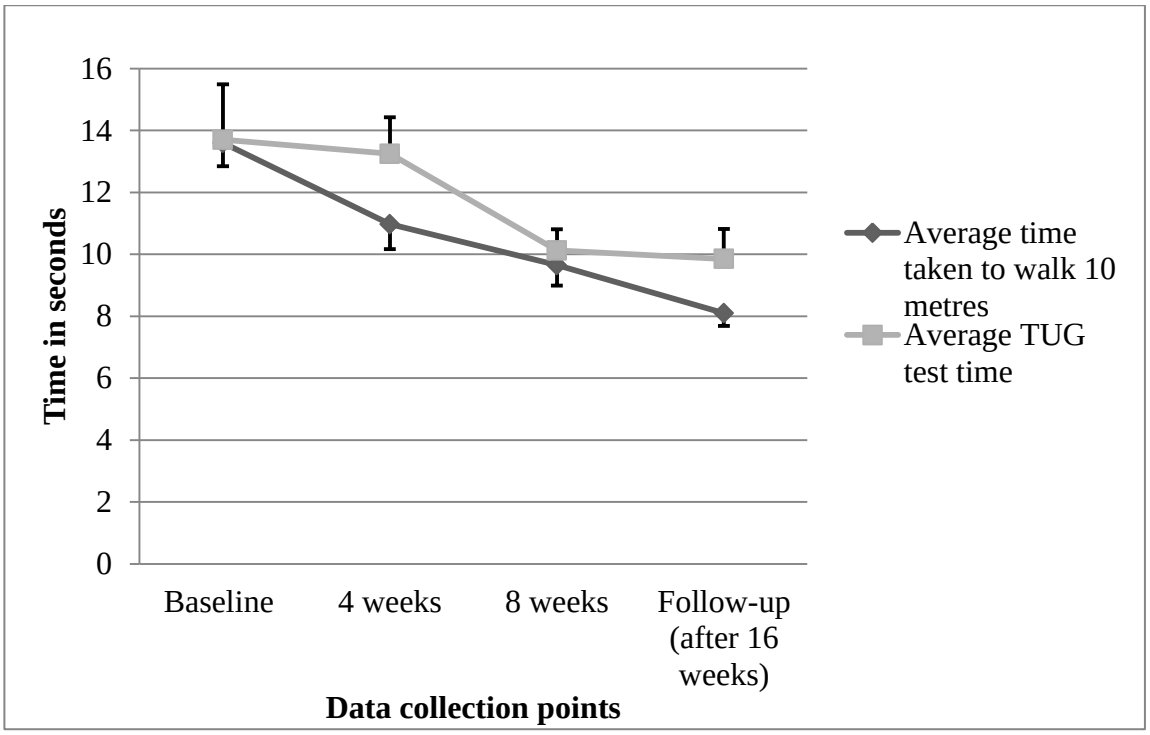

Figure 7.16: Average time taken to complete the 10MWT and the TUG test by participant three

7.5.5.2.7. Timed Up and Go test

The average time taken to complete the TUG test decreased from 13.7 ± 1.8 seconds in the first visit to 9.9 ± 1.0 seconds in the final visit, a decrease of 3.9 seconds (32.7%) (Figure 7.16). The decrease in the time was largest between the second and third data collection points.

7.5.5.2.8. Stroke Self-Efficacy Questionnaire

The SSEQ scores improved by 8 points from the first assessment (114 points) to the final assessment (122 points) (Figure 7.17). However, the SSEQ scores decreased gradually over the second and third visits and then improved during the final visit.

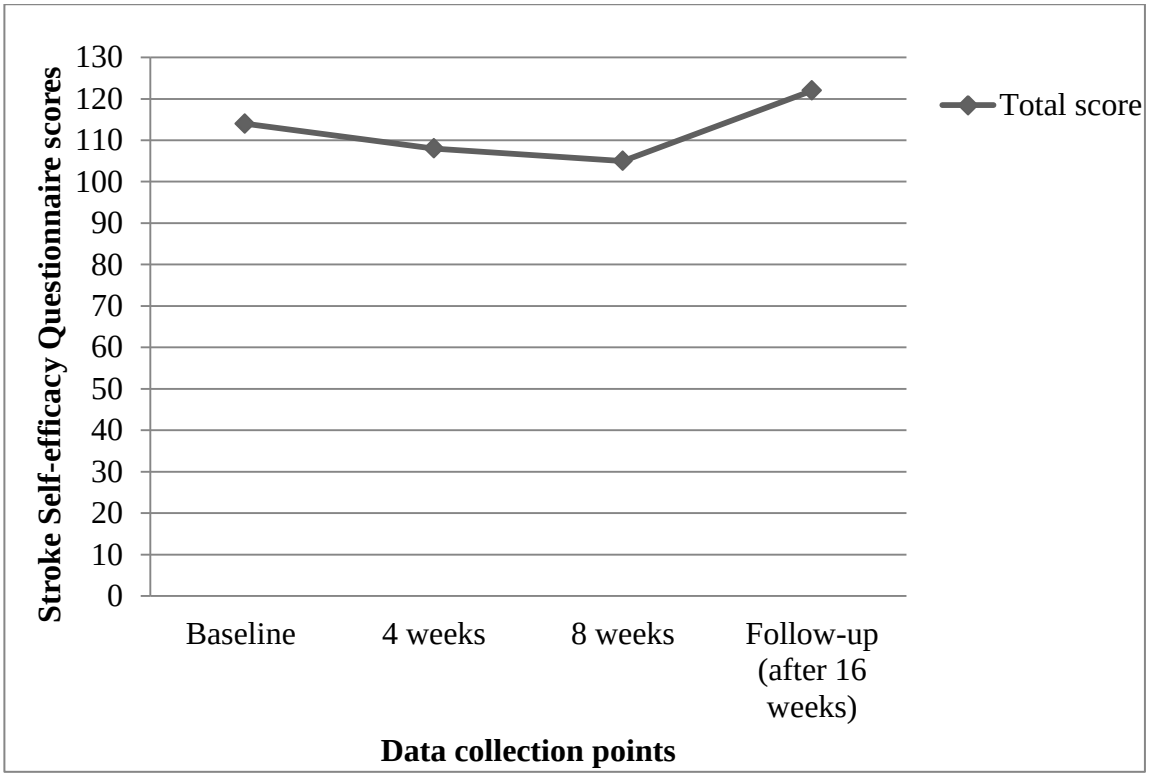

Figure 7.17: SSEQ scores for participant three

7.5.5.2.9. Stroke Impact Scale

Six domains of the SIS showed improvement between the first and final assessments, while the domain of strength remained at the same level and the domain of communication declined (Figure 7.18). Over all the visits, five domains had scores between 80 and 100, while the domains of strength, and social participation remained slightly lower, between 60 and 70. Only the domain of emotion had scores in the 40's,

however, this was only during the initial two visits, after which the scores improved to 66.7 during the final visit.

As for the question on stroke recovery, the participant's scores improved from an initial score of 70, to a score of 85 in the final visit, implying recovery, although there was a dip to a score of 68 during the assessment at eight weeks.

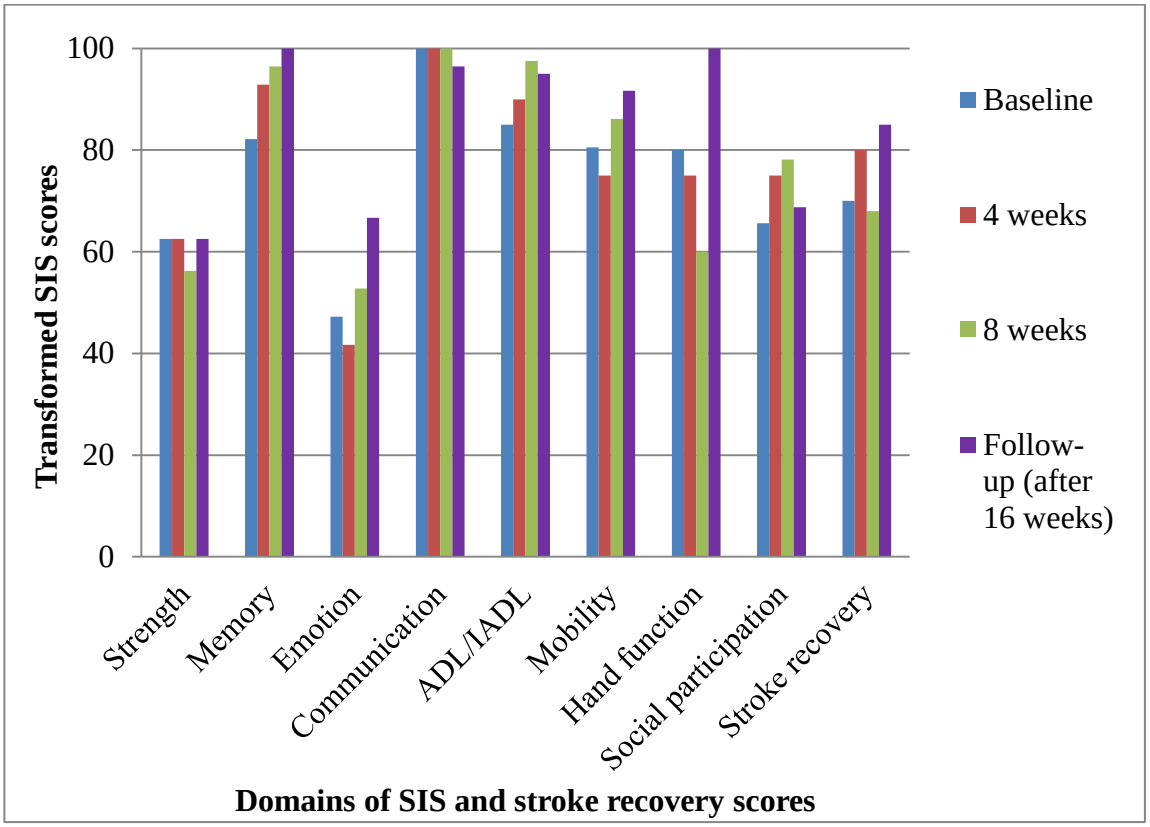

Figure 7.18: Transformed scores of the SIS for participant three

Key: SIS – Stroke Impact Scale; ADL – Activities of Daily Living; IADL – Instrumental Activities of Daily Living.

7.5.5.3. Experiences of goal setting

As with participants one and two, three themes were created for participant three (Figure 7.19). Two themes considered the perceptions and attitudes of the participant relating to

goal setting. The participant's familiarity with goal setting appeared to link both the perceptions and attitudes, and therefore, was created as a third linking theme. The themes and contributing sub-themes are discussed next. All the interpretive themes are supported with illustrative text.

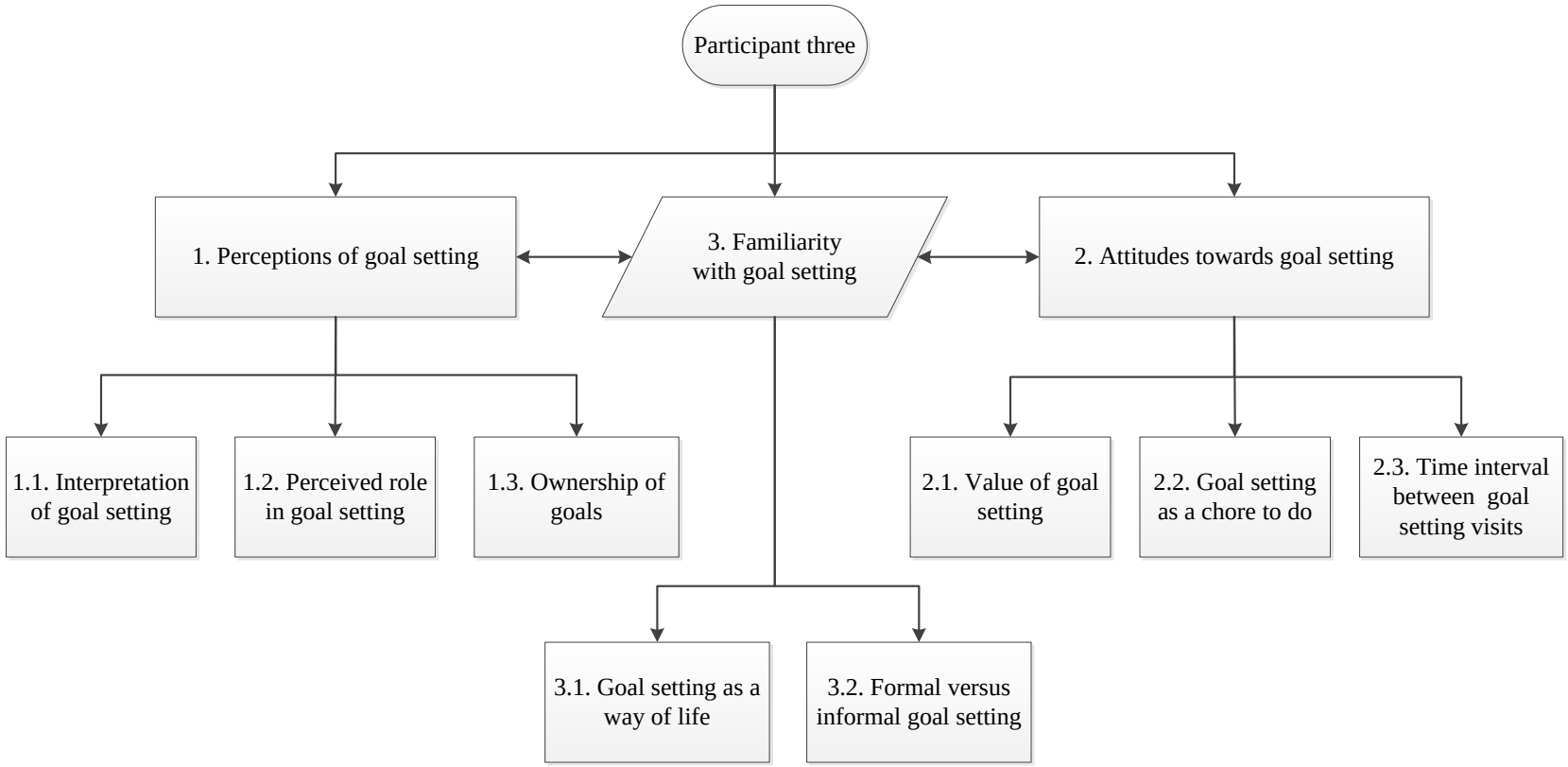

Figure 7.19: Theme structure of experiences – participant three

7.5.5.3.1. Perceptions of goal setting

The participant's perceptions of goal setting were shaped by three sub-themes, namely the interpretation of goal setting, the role within goal setting and the ownership of goals. Each of these second level themes is discussed in the following sub-sections.

Interpretation of goal setting

The participant expressed his understanding of the term 'goal setting' by using specific terminology that could be linked with the definition of goal setting used in this project and the general principles of goal setting. These specific terms included: "setting targets[8]", "putting plans together for that[8]", "writing them down", "putting measures in place[8]", and "being realistic[20]".

Role within goal setting

During the interview, the participant reflected on how he thought he contributed or was expected to contribute to the goal setting process. He felt that "self-responsibility" and 'honesty" were his key roles in goal setting, as demonstrated in the quote below:

> [18]"My role first was to be honest. It is probably the most important thing. I had a responsibility to actually do it … My role was to think about it clearly, be honest, and actually do it."

When probed by the interviewer to explain what he meant by honesty, he answered "being realistic when setting goals[20]" and "not pretending to either to the researcher or myself whether I was being successful or not[22]". The participant also thought that he had "enough brain to think[28]" and to decide his goals. He also recognised that stroke could affect an individual's capability of setting goals and that he was "lucky that the stroke didn't mess up my head too much[48]".

Ownership of goals

The participant was confident that the goals set were his own and that he was "not influenced[26]" by the researcher.

7.5.5.3.2. Attitudes towards goal setting

The participant's attitudes towards goal setting formed the second theme and three sub-themes contributed to this main theme, namely: value of goal setting, goal setting as a chore, and time interval between goal setting visits.

Value of goal setting

The participant explained that goal setting as a process was valuable because, "only by writing it [goals] down and looking back on it you can get a measure of your progress". He also felt that the discussion on goal achievement was "meaningful[68]" for the following reason:

> [68]"… because it gave me a chance to actually put into words how I was feeling about things and it will be [shown] on recordings … it was discussed meaningfully without pressure"

Goal setting as a chore

Although the participant described the goal setting process as valuable, he was particularly frustrated on completing the workbook for every visit and described it as "annoying[46]". He suggested the following for future:

> [78]**Participant three:** All I would say, is that, if people are going to use these things [goal setting workbook], then the less work or so … less can be more.
>
> [79]**Interviewer:** Fewer words?

[80]**Participant 3:** Yes, that's right … I would say the less, not the less they have to think about, but the less the number of things they have to go through [the better].

Time interval between goal setting visits

The participant thought that he was given sufficient time to think about and decide his goals. Similarly, he felt that the time gap between sessions where goal progression was discussed was appropriate. The participant reasoned that this time gap was required for the following reasons:

[66]"It [time interval between goal setting visits] is about right because unless you have set very narrow and time-limited goals, like I intend to get the bus on Wednesday, you need some time to [do] as things do not always come straight away".

7.5.5.3.3. Familiarity with goal setting

The participant's perceptions and attitudes relating to goal setting appeared to be linked to his familiarity with goal setting. This participant had used goal setting both as part of his personal life and professional life. Due to this, he viewed goal setting as a way of life and was of a view that everyone set goals, as evident in the following quote:

[76]"I always have [used goal setting] and it … becomes the way of one's approach to life … irrespective of my [or] one's health, goal setting is just something people do and you are doing it in a more formalised manner".

As seen in the above quote, his familiarity with and understanding of goal setting made him appreciate the formality introduced within the goal setting in this study. In several instances, he compared his usual informal method of goal setting to the formal method of goal setting (used in this study), as illustrated in the two quotes below:

[6]"The concept [of goal setting] is not [new], but the book is obviously just a variation on it".

[10]"Not [used goal setting] formally [in personal life]. Everybody has their dreams and goals but not in a structured regime or anything".

The participant also recognised the value of formality on most occasions and felt that if goal setting is not done formally then "it becomes perhaps more subjective than it needs to be[14]". Although he found the goal setting workbook an annoyance, his frustration was towards the level of the attention given to the goal monitoring, rather than the entire workbook. Hence, his suggestion of "less is more[78]".

7.5.5.3.4. Summary of experiences of goal setting of participant three

Participant three was familiar with goal setting and understood his role within the goal setting process. He was also able to identify the differences between informal and formal methods of goal setting and appreciated the value of the latter.

7.5.5.4. Feasibility of goal setting

The goal setting intervention was applied to the participant without any difficulties. The participant was able to set goals and fully participate in the goal setting discussions. The value of the process was also understood by the participant. Goals and priorities changed over the course of the study due to the participant's personal life. His fairly low scores on the emotion domain of the SIS could be a reflection of his personal circumstances. His understanding of goal setting enabled him to modify his goals and time frames as needed. For the goals that were followed through, there were mixed results regarding goal achievement. It should be noted that the time frames for the goals which were not achieved were not within the duration of the current study. The participant also felt disappointed with his physical activity levels during the final visit. However, all the

outcome measures, including the activPAL™, showed positive changes between baseline and final follow-up assessment. It should be recognised that some of the goals set by the participant were ambitious and this may have impacted on his perception of the level of goal achievement. It was also unclear whether the participant had higher expectations, and therefore was not able to see the improvements. No problems were encountered with the application of the selected outcome measures. Compliance with the intervention and the study were good. Therefore, it could be concluded that goal setting was a feasible intervention for participant three.

7.5.6. **Case study four**

Participant four was a 66 year old male who had a left sided stroke seven months prior to the start of the study. The participant had issues with memory due to stroke. Therefore, he carried a notebook with him at all times, in which he wrote down important information. His short term memory was more affected than his long-term memory. The participant had retired pre-stroke.

7.5.6.1. Study pathway

The participant was referred to the circuit session of the EaS service. He had two baseline assessments as planned. During the second visit, goal setting discussions also took place as per protocol and an appointment was made for the third visit. When the participant was contacted for re-confirmation of this appointment, he expressed that goal setting was not suitable for him, and wanted to opt out of the intervention. However, he was willing to be involved in the other assessments. Therefore, no further goal setting sessions were conducted for this participant. He participated in the outcome measures assessment at 12 weeks, during which he also had the interview on the experiences of goal setting. The participant did not attend the EaS classes during the course of his involvement in the current study.

7.5.6.2. Description of results

7.5.6.2.1. Goal setting discussions

The researcher conducted one goal setting session with the participant. During this session, the participant did not identify any goals and felt that physical activity was not important for him as he was physically inactive pre-stroke. The benefits of physical activity were explained to the participant. The COPM and its examples were used to help the participant identify his problems and thereby his goals. However, he was not able to come up with any goals. He felt that he may need more time. The participant

informed the researcher that an appointment was made for him to meet an Exercise Instructor of the EaS service. Therefore, it was decided that the participant would attend the class first and that this may help him set goals. Due to his issues with memory and to help the participant with goal setting, the goal setting workbook was given to him. Information on goal setting and how to use the workbook were included in the workbook in writing and it was believed that this would also help the participant to set goals.

The participant decided that he did not have any goals and therefore, opted out of the goal setting intervention.

7.5.6.2.2. Free living physical activity

On average, the participant wore the activPAL™ for 16.5 ± 0.3 hours each day over five days across all the visits, of which 15.2 ± 0.2 hours were spent in sitting/lying, and the remaining 1.3 ± 0.1 hours spent upright. The average time spent in sitting/lying and upright in a day, over the data collection points, is presented as Figure 7.20. The time spent in sitting/lying and upright remained nearly the same throughout, with a 0.5% (i.e. 0.1 hours per day) decrease in physical activity behaviour between baseline and follow-up. The participant spent around 93% of his waking hours in sitting/lying, and only 7% of the time was spent upright in activity. The small SD (as denoted by the error bars) demonstrates that there was a low variation in the time spent in various positions between days of the data collection period.

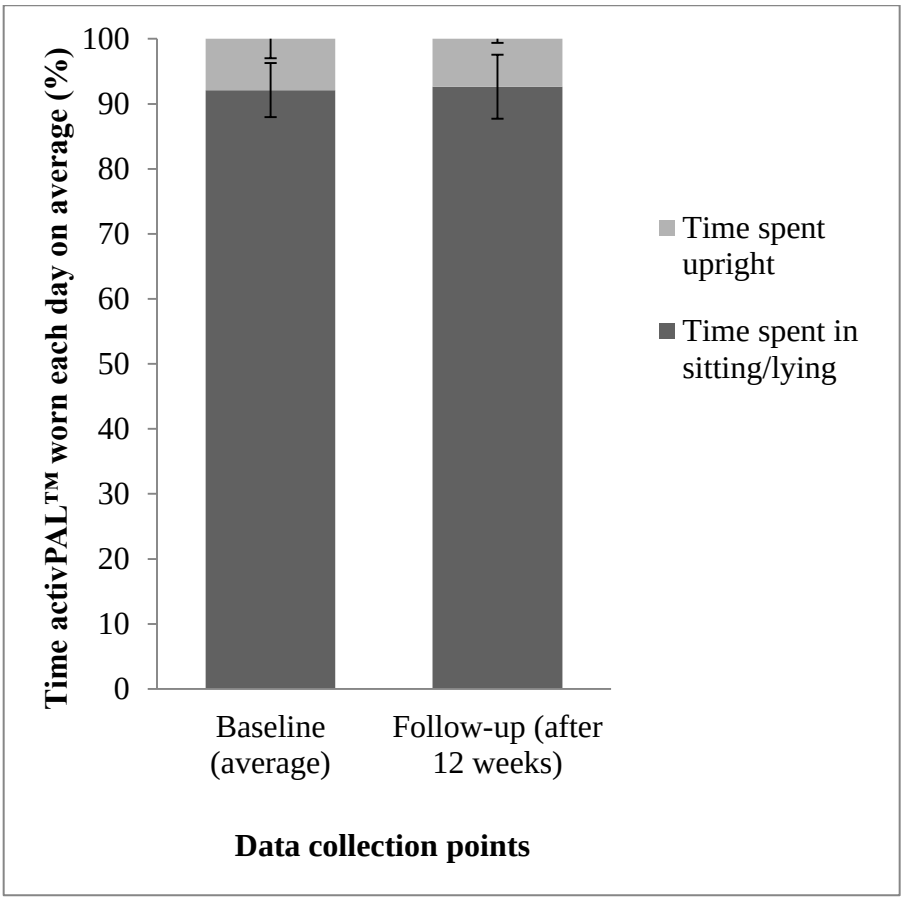

Figure 7.20: Average time spent in a day in sitting/lying and upright by participant four

7.5.6.2.3. Ten metre walk test

The participant had a mean gait speed of 0.67 m/s at baseline. The average time taken to walk ten metres decreased between the baseline measurement (14.9 ± 0.7 seconds) and follow-up (14.5 ± 0.4 seconds) (Figure 7.21). However, this decrease was very small, at 0.4 seconds, an improvement of only 2.9%.

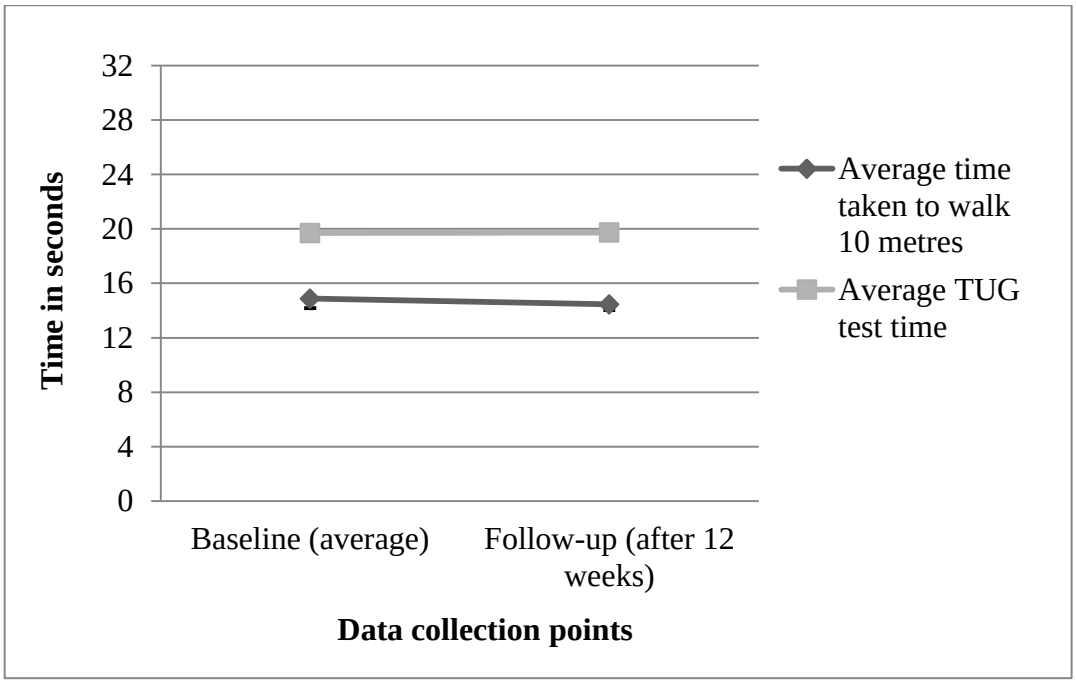

Figure 7.21: Average time taken to complete the 10MWT and the TUG test by participant four

7.5.6.2.4. Timed Up and Go test

The average time taken to complete the TUG tests did not change between the baseline measurement and the follow-up assessment (Figure 7.21), and remained at 19.7 ± 0.4 seconds.

7.5.6.2.5. Stroke Self-Efficacy Questionnaire

The SSEQ scores improved by 8 points from the baseline scores (110 points) to final assessment (118 points) (Figure 7.22).

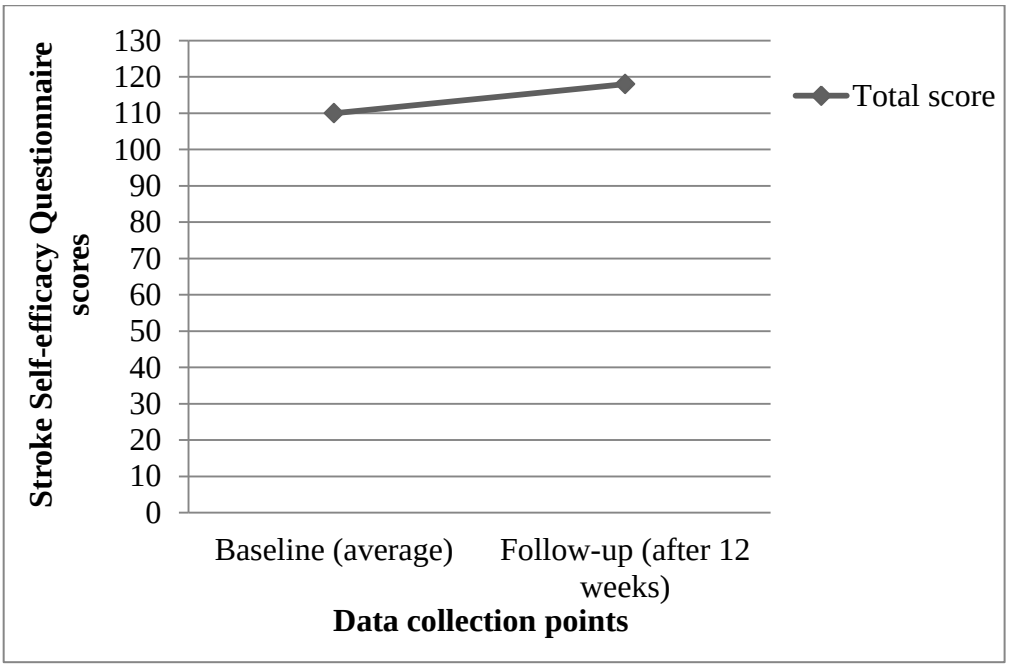

Figure 7.22: SSEQ scores for participant four

7.5.6.2.6. Stroke Impact Scale

All domains of the SIS, excluding memory, showed improvements between the average baseline scores and the scores at the final follow-up assessment (Figure 7.23). The scores for hand function reached the maximum of 100 during the final assessment. Only the scores for the memory domain remained low at an average of 43.8 across the visits, highlighting the participant's issues with memory.

As for the question on stroke recovery, the participant's score improved from an average baseline score of 45 to a score of 60 in the final visit, implying slight recovery. However, the scores were low implying that the participant's perception of recovery from stroke was not high.

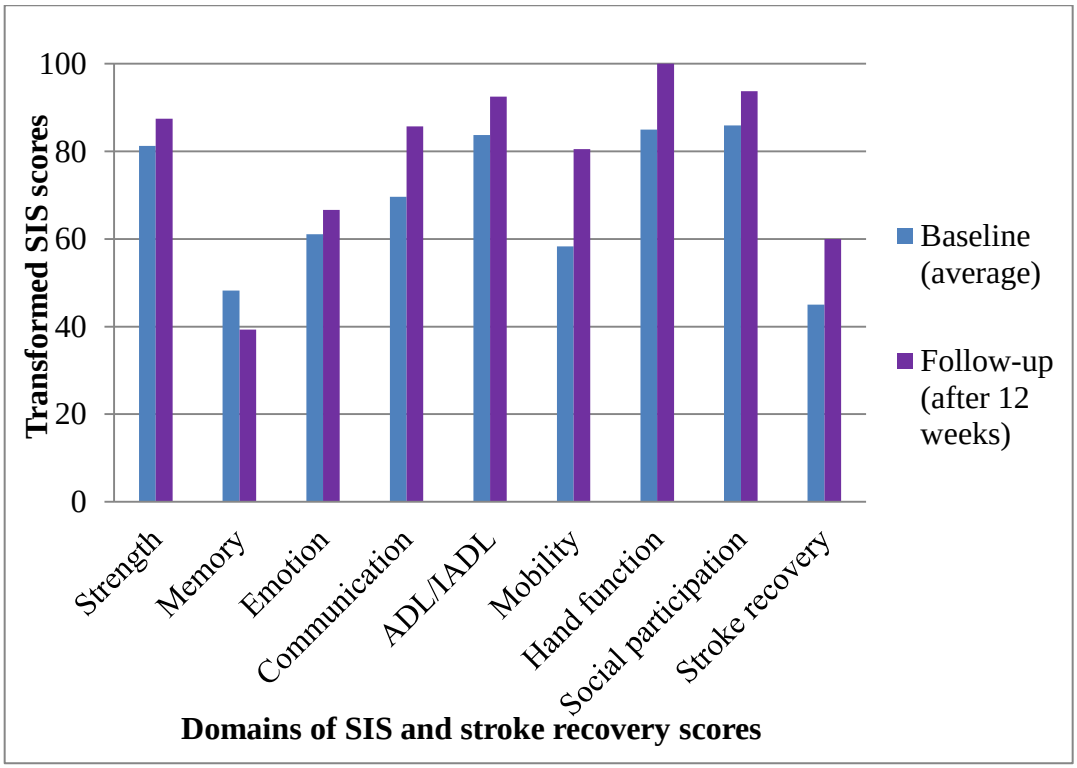

Figure 7.23: Transformed scores of the SIS for participant four

Key: SIS – Stroke Impact Scale; ADL – Activities of Daily Living; IADL – Instrumental Activities of Daily Living.

7.5.6.3. Experiences of goal setting

As with case study two, the participant's perceptions and attitudes regarding goal setting were considered to be independent themes and the participant's individual characteristics formed a third and linking theme. The theme structure is schematically presented as Figure 7.24. This is followed by discussion of the themes and the sub-themes, supported by illustrative text.

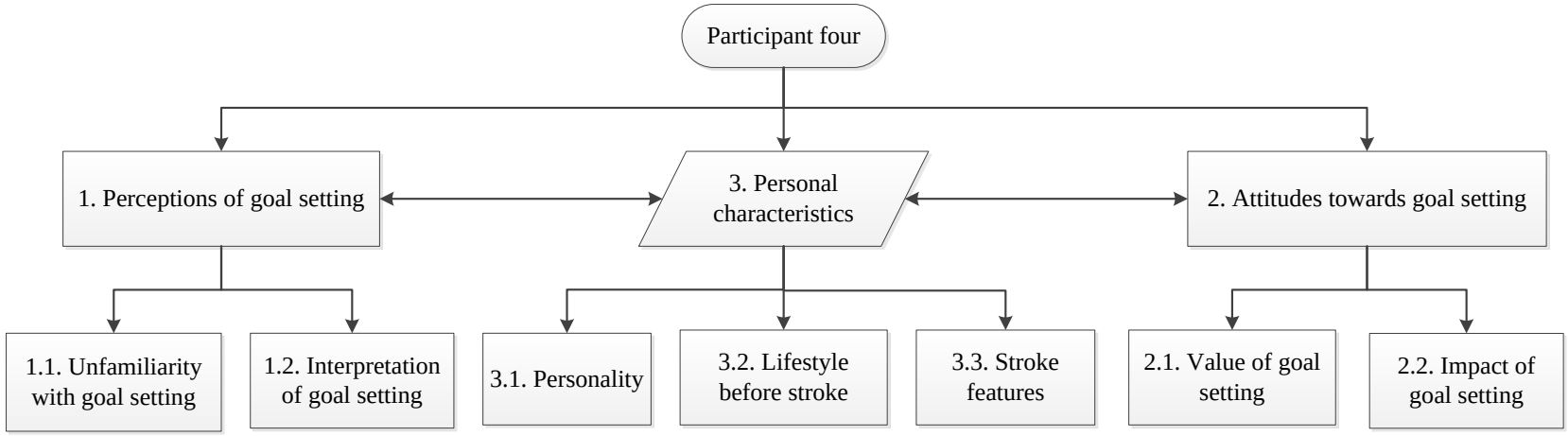

Figure 7.24: Theme structure of experiences – participant four

7.5.6.3.1. Perceptions of goal setting

The participant stated that he had "never really been involved in goal setting before[6]" and considered goal setting to be a "totally new experience[10]". Although the participant had not set goals before, he understood the purpose of goal setting, as evident in the quote below:

> [14]"The whole purpose of this [goal setting] was to find out what my goals were and then do as much as possible and make it possible …"

The participant was also able to articulate the principles within goal setting, such as "not setting impossible goals[22]", and "be practical[22]".

7.5.6.3.2. Attitudes towards goal setting

The participant felt that goal setting was not actually relevant to him and saw no value in it. The participant answered "no[52,54]" when asked if goal setting had an impact on his life and also when asked if he would use goal setting in the future.

7.5.6.3.3. Personal characteristics

The participant extensively discussed his personality, life before stroke, and the effect of stroke on his life. Aspects of this discussion appeared to relate to both his perceptions of, and attitudes towards, goal setting, and hence 'personal characteristics' was considered a linking theme.

During the interview, the participant talked about his "laid back[14]" personality and felt "guilty[24]" about not using the goal setting techniques and not "getting involved[48]". This personality seemed to be related to his lifestyle both before and after stroke. The participant described his lifestyle as "simple old fashioned[8]" and "ordinary[12]", but something that "works [well] for[8]" him. He also referred to his lifestyle as "boring[52]" and "sedate[52]". On coping with stroke, he reflected that although he "did not like[32]" the

stroke, he knew he could not do anything about it and therefore "came to terms with it very quickly[32]". Throughout the interview, he expressed that he was "very content" with his life and felt there was no need to alter it. This was interpreted as one of the reasons for the participant not taking up goal setting and opting out of the goal setting intervention. The following quote summarises the participant's thoughts and reflects his contentedness with his life:

> [26]"I think after the stroke I have been working well … other than my memory, my effects have been smallish. So I have managed to cope reasonably well with it. I have not got any depression or mood [changes] … [From that] point of view, things have really been much about the same as it was before. So [I am] less inclined to [change]. I am quite happy, comfortable house, comfortable lifestyle. [I am] not doing a lot, but it is not causing me any depression, or anything. On any side, it is not a problem. I am happy, settled. My family is pleased".

Although the participant did not highlight his memory as a major issue, he made several references to his memory when asked about goal setting and the goal setting workbook (Table 7.9).

Table 7.9: Illustrative text to highlight memory issues of participant four in relation to goal setting

[22]I just went with the flow [the process of goal setting]. My memory isn't very good anyway; I would not remember what happened. [So] basically I just go with the flow.
[33]**Interviewer:** You said you did not use it [goal setting workbook], can you explain to me what was it that got in the way of using it? [34]**Participant four**: My memory is a lot of time useless. I need to look at it to know what is in it. [35]**Interviewer:** So remembering to actually pick it up, [36]**Participant four:** Well, that was a problem, I did not. I should have read that anyway, but the thing is even if I had read it, I would not have remembered.
[56]In the first place, if I read that [workbook] now, by the time I go home, I would not have a clue as to what is in it. I will need to pick it up and start all over again.

7.5.6.3.4. Summary of experiences of goal setting of participant four

Overall, the participant understood goal setting, however, his personal characteristics such as his lifestyle and issue with memory influenced his involvement in goal setting. As the participant opted out of the goal setting intervention, no value or impact was experienced.

7.5.6.4. Feasibility of goal setting

The participant was able to complete all the outcome measures without difficulty. The participant decided to opt out of the goal setting intervention because he felt that he had no goals, and that goal setting was not relevant to him. The participant did not attend the EaS classes during his involvement in the current study.

Regarding flexibility in terms of setting goals, acceptability of the goal setting intervention, and compliance with the intervention and study, it is concluded that goal setting was not a feasible or a valuable intervention for participant four.

7.5.7. **Synthesis of quantitative data**

The quantitative data from the individual participants for each outcome measure was grouped together and changes between participants were compared. Where possible and available, data from this study was compared with normative data and the changes observed were compared with the minimal detectable change (MDC) (i.e. the amount by which a patient's score needs to change to be sure the change is greater than measurement error) and minimally clinically important difference (MCID) (i.e. the smallest change in an outcome measure that would be considered important by the client or clinician) (Donoghue et al. 2009). The comparison for each outcome measure is presented in the following sub-sections.

7.5.7.1. Canadian Occupational Performance Measure

Participant four did not set any goals and therefore had no COPM scores. The remaining three participants showed an overall average improvement between two and three points on both COPM-P and COPM-S scores between the baseline and final assessments. However, it should be noted that participants two and three had individual goals that were not achieved during the study duration.

A COPM change score of two or more points is considered as a clinically significant change (Law et al. 2005). In line with this, it can be seen that all three participants had a clinically significant change on both the COPM-P and COPM-S change scores between baseline and final assessment. Eyssen et al. (2005) in their study of 95 patients of varying diagnosis concluded that mean scores of COPM should be used for individual assessment rather than the individual scores. However, the findings from the current

study has highlighted that the non-achievement of some individual goals should not be overlooked.

7.5.7.2. Free living physical activity

The average time spent each day in sitting/lying and upright which was obtained from the activPAL™ was compared between participants across the data collection points and is presented as Figure 7.25. Participants one and three showed improvements in physical activity behaviour, while participant two declined and participant four showed no change. From the figure, it could be seen that participant one was the most physically active person among the four participants, followed by participant three, two, and four.

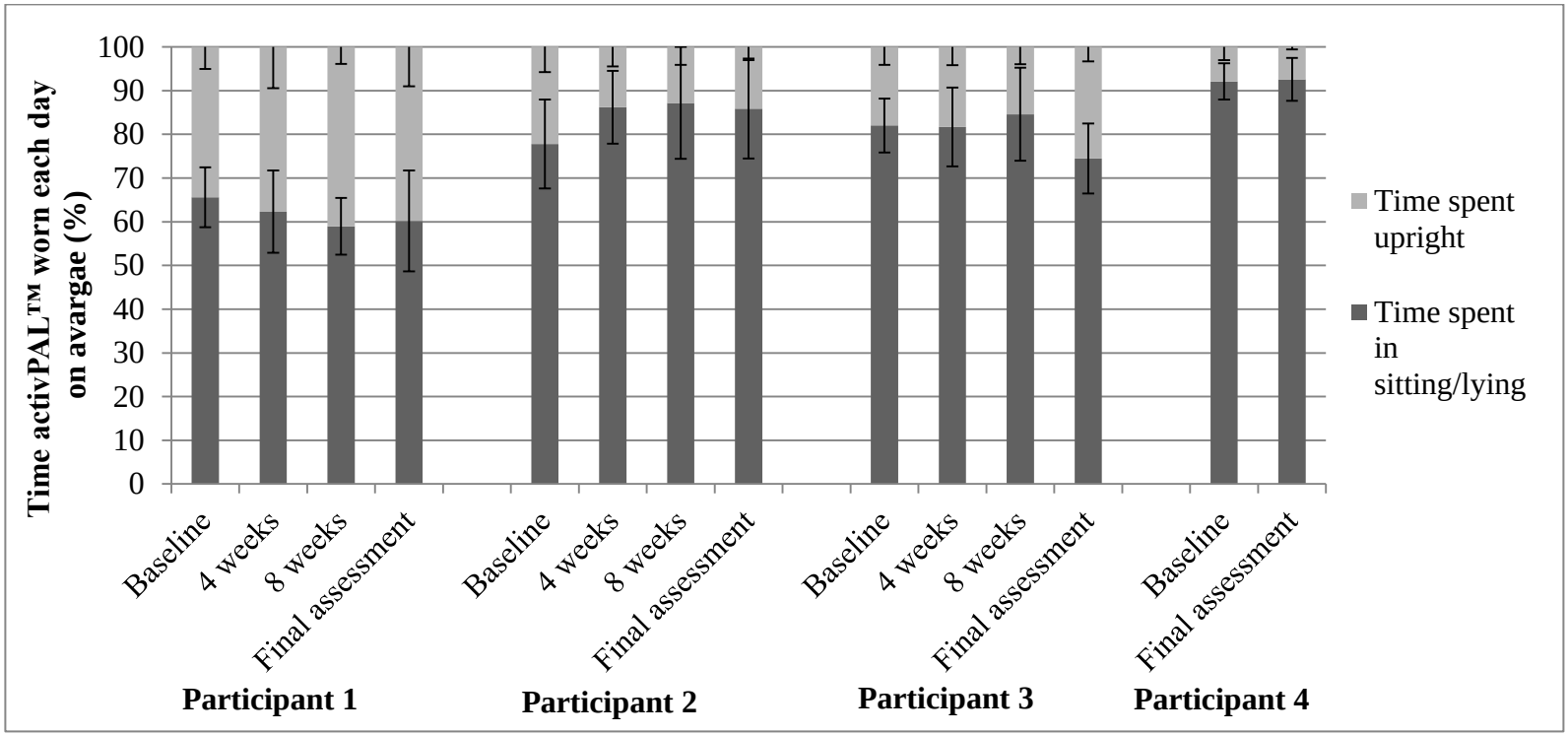

Figure 7.25: Comparison of the time spent in sitting/lying and upright each day on average between all participants across data collection points

Key: Baseline data represents average baseline for all participants excluding participant three who had only one baseline assessment; final assessment was conducted at the end of intervention (12 weeks) for participant one and two, as follow-up assessment after 16 weeks for participant three, and as follow-up assessment after 12 weeks for participant four; participant four did not have assessments at four and eight weeks.

The physical activity pattern of participants from this study was compared with data presented in other studies that used activPAL™ as one of their outcome measures (Touillet et al. 2010, Kottink et al. 2007, Britton et al. 2008). In the study of Kottink et al. (2007), participants with stroke spent around 75% of the waking hours in sitting. Based on this, it would appear that participant one was more physically active than this sub-group, while participant four was much less so throughout the study. However, it should be noted these data were based on a small sample of 21 participants who were five to nine years post-stroke (Kottink et al. 2007). Comparisons could not be made with the other studies, as they measured either number of steps (Touillet et al. 2010), or number of transitions (Britton et al. 2008), neither of which was considered in the current study.

It was of interest to identify whether participants were meeting the recommended levels of physical activity for stroke survivors by the end of the current study. However, these recommendations either refer to the intensity of the activity performed (Gordon et al. 2004) or the number of steps (Field et al. 2013, Rand et al. 2009), neither of which was available or considered in the current study. Therefore, no comparisons could be made. If the psychometric properties of the activPAL™ for the number of steps and number of transitions are improved, this would allow for comparison with the current recommendations, which should be considered for future research.

The American Heart Association recommends that a stroke survivor should undertake 20-40 minutes of continuous (or multiple sessions of ten minutes) moderate intensity aerobic training three to seven days a week, and one to three sets of 10–15 repetitions of eight to ten exercises involving the major muscle groups, two to three days per week (Gordon et al. 2004). Although the intensity of the activity performed cannot be directly measured by the activPAL™, it was of interest to identify whether any of the participants were involved in continuous activity for more than 40 minutes each day during the final assessment. The relevant data were explored and revealed that only

participant one had several bouts of continuous activity lasting more than 40 minutes every day, some periods exceeding an hour. Participant three had some bouts of continuous activity lasting around 30 minutes on most days, although less than participant one. Even fewer bouts of continuous activity lasting around 30 minutes were identified for participant two, while none were identified for participant four. Based on this data, it could be speculated that participant one was meeting the current recommendation. Similar speculations could not be made for participants two and three; however, the increase in physical activity demonstrated by participant three was encouraging, but the opposite was the case for participant two. The sedentary behaviour of participant four was a cause for concern, albeit not for the participant himself.

7.5.7.3. Ten metre walk test

The average time taken to walk ten metres for all the participants over the data collection points is presented graphically as Figure 7.26. On comparison, participant one had the shortest time overall while participant two took the longest time to complete the 10MWT. Although participant three had the shortest time of 8.1 seconds in the final assessment period, it should be noted that his final assessment was a follow-up assessment after 16 weeks. Interestingly, participant two took nearly twice the time to complete the 10MWT when compared with participant one. In terms of improvement, participant three improved the most on this outcome measure (5.5 seconds: 50.7%), while participant four had a decline between the baseline and final assessment.

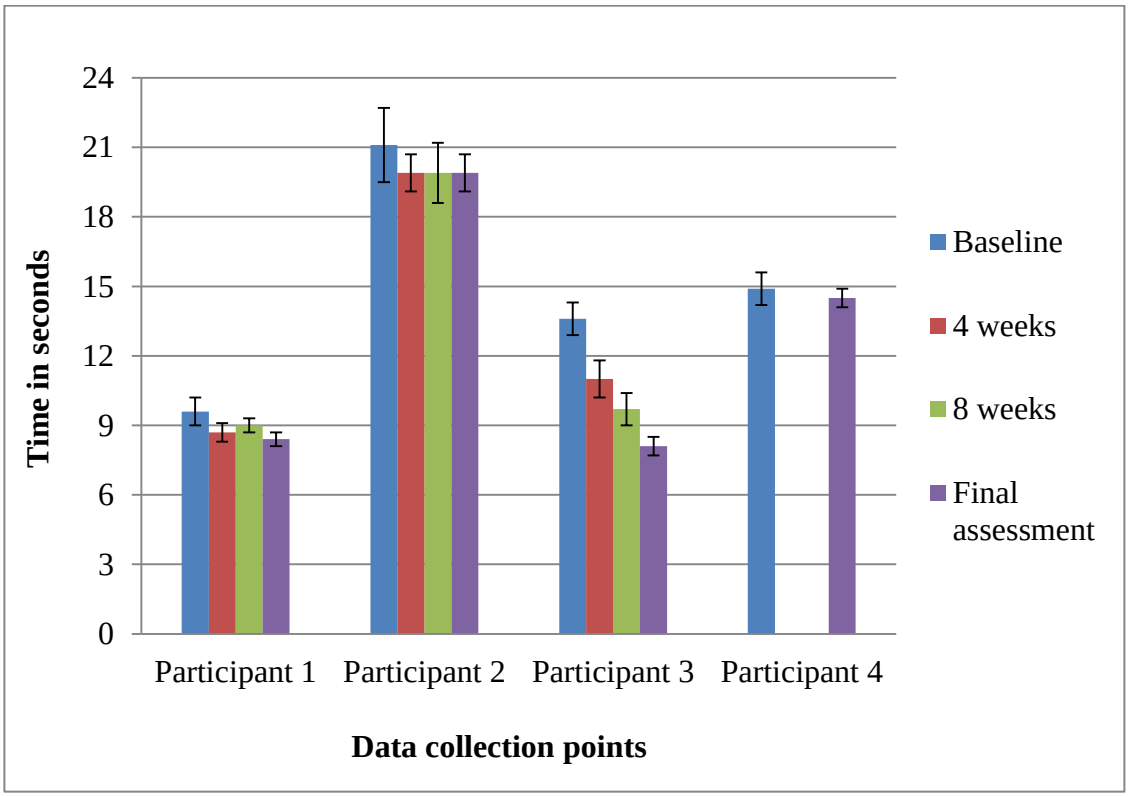

Figure 7.26: Comparison of average time taken to walk ten metres between all participants across data collection points

Key: Baseline data represents the average baseline for all participants excluding participant three who had only one baseline assessment; final assessment was conducted at the end of intervention (12 weeks) for participant one and two, as follow-up assessment after 16 weeks for participant three, and as follow-up assessment after 12 weeks for participant four; participant four did not have assessments at four and eight weeks.

The mean gait speed of the participants at baseline, calculated from the 10MWT, varied between 0.47 m/s in participant two, to 1.04 m/s in participant one. Based on normative data for this population (0.84 ± 0.3 m/s) (Rand et al. 2009, Severinsen et al. 2011), it can be seen that participant one had a much higher gait speed and participant two much lower. The mean gait speed of participant three improved above the normative value

during the final assessment (1.23 m/s). However, no such change was evident for participants two and four. No MDC value for the mean gait speed (calculated from the 10MWT) was available from the literature for comparison and therefore, the MDC value from study three (0.14 m/s) was used (section 6.5.10). The MCID, as demonstrated in two studies, was between 0.14 and 0.16 m/s (Perera et al. 2006, Tilson et al. 2010). In line with these, a MDC and a MCID was evident for gait speed change between average baseline and final assessment in participants one (0.15 m/s) and three (0.5m/s).

7.5.7.4. Timed Up and Go test

Figure 7.27 provides a graphical representation of the TUG scores of all participants across the data collection points. As with the 10MWT, participant two took more than twice the time to complete the TUG test when compared with participant one. Only participant four showed a decline in this measure between baseline and final assessment. Similar to the 10MWT, participant three showed the highest improvement at 32.7% (3.9 seconds improvement) between baseline and final assessment. Interestingly, participants one and three had a similar TUG test time of 9.9 seconds at the final assessment. However, it should be noted that the final assessment for participant three was conducted at a later time period of 16 weeks rather than 12 weeks.

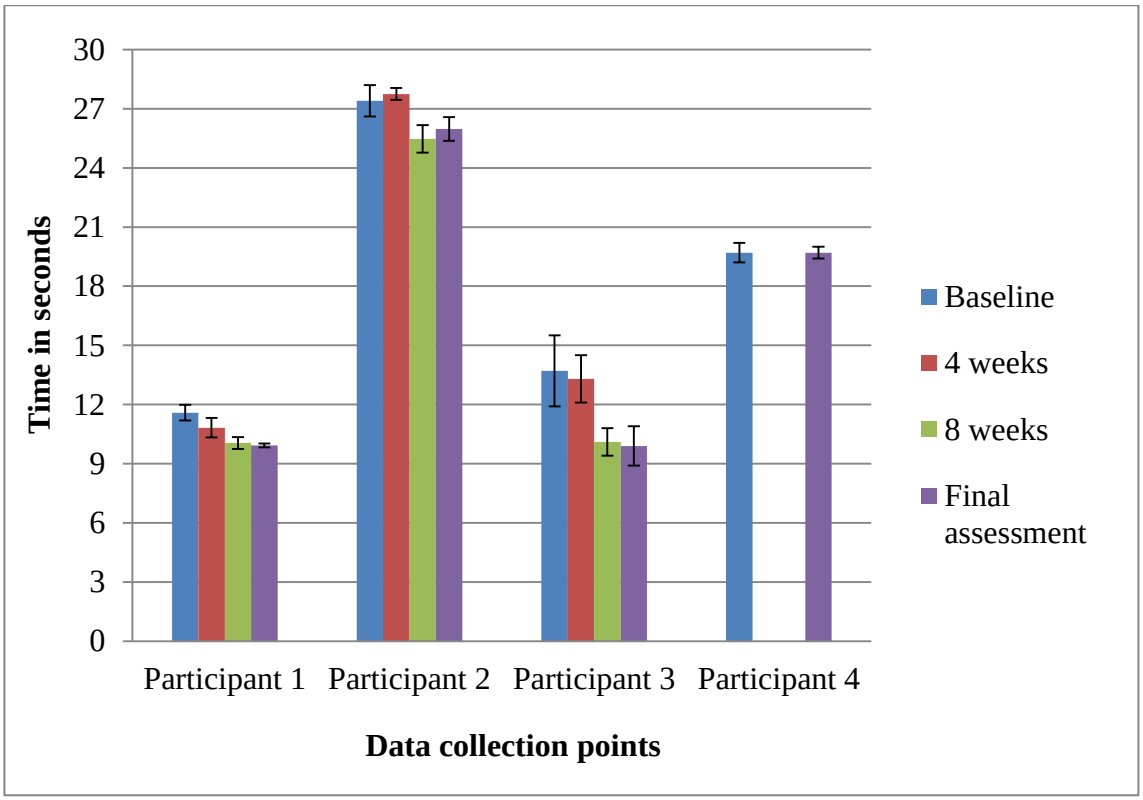

Figure 7.27: Comparison of average time taken for the TUG test between all participants across data collection points

Key: Baseline data represents the average baseline for all participants excluding participant three who had only one baseline assessment; final assessment was conducted at the end of intervention (12 weeks) for participant one and two, as follow-up assessment after 16 weeks for participant three, and as follow-up assessment after 12 weeks for participant four; participant four did not have assessments at four and eight weeks.

Normative values for this measure for this population were not available, to the best of the researcher's knowledge. However, the baseline TUG test scores of participants two, three and four in the current study (between 13.6 and 21.1 seconds), were lower than the normative values established for a community-dwelling healthy elderly population (8 ± 2 seconds) (Steffen et al. 2002), thereby suggesting that these participants had balance limitations. However, participant one had baseline scores within the normative values for the community-dwelling elderly, highlighting the high functional ability of this

participant. This pattern was evident at the final assessment as well, excluding participant three who had scores within the normative value at this assessment.

Flansbjer et al. (2005) identified that a 2.9 second change in the TUG test score in chronic stroke patients was indicative of a MDC for this measure. However, the MDC value obtained from study three was lower at 1.97 seconds (section 6.5.10). As time since stroke in the current study was more similar to the sample of study three, the lower MDC value was used for comparison. Based on this, only participant three achieved a change score (between baseline and final assessment) higher than the MDC (3.9 seconds). Since participant one already had normative TUG scores for healthy elderly at baseline, it could have been difficult for this participant to achieve a greater improvement. No MCID scores were available for this measure from the published literature.

7.5.7.5. Stroke Self-Efficacy Questionnaire

All participants showed positive changes on the SSEQ between the baseline and final assessments (Figure 7.28). Participant two had low scores on the SSEQ throughout the study on comparison with others, but interestingly, he improved the most (13.2%, a change of 12 points). Participant one had scores close to the maximum throughout the study, and therefore, the chances for high improvement may have not been possible.

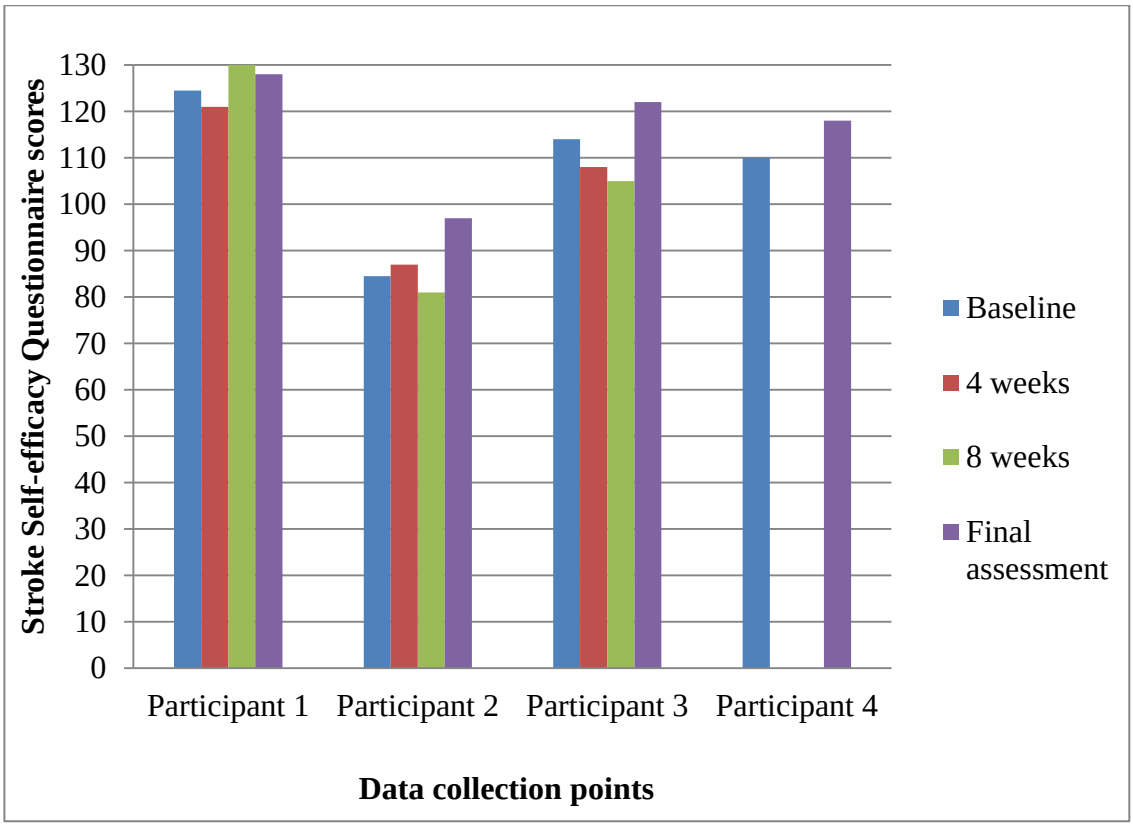

Figure 7.28: Comparison of SSEQ scores between all participants across data collection points

Key: Baseline data represents the average baseline for all participants excluding participant three who had only one baseline assessment; final assessment was conducted at the end of intervention (12 weeks) for participant one and two, as follow-up assessment after 16 weeks for participant three, and as follow-up assessment after 12 weeks for participant four; participant four did not have assessments at four and eight weeks.

As the SSEQ was a recently developed measure in comparison with the others, no normative data, MDC or MCID were available for comparison.

Participant one had SSEQ scores between 121 and 130 out of a maximum possible score of 130. These high scores may be indicative of ceiling effects within measure, however, this only applied to one single participant in the study.

As explained in the background chapter (section 2.9.4), this measure was chosen for its relevance to stroke and the SCT. Since the measure considered various aspects of stroke such as mobility, dressing, eating, and exercising, to name a few, the total score was a reflection of the individual's overall self-efficacy. However, as the target behaviour with the goal setting intervention was physical activity, the possibility of including a more specific self-efficacy measure relating to exercise, such as the Self-Efficacy for Exercise Scale (SEE), could be considered, in addition to the SSEQ. The SEE measures the confidence of an individual for the performance of 20 minutes of exercise three times per week over 11 different criteria, for example when exercising alone, when stressed, when depressed, and when not enjoying the activity (Resnick and Jenkins 2000).

7.5.7.6. Stroke Impact Scale

Only participant one showed improvements in all the domains of the SIS between baseline and final assessments. Moreover, this participant had higher scores across all the domains on comparison with the other participants. Participants three and four declined in one domain each, communication and memory respectively, while participant two declined in four domains between baseline and the final assessment.

As explained in chapter 2, section 2.9.5, the domains of strength, hand function, mobility, and ADL/IADL were added together to calculate the physical dimension score, which was then compared between participants across the data collection points (Figure 7.29). From the figure, it can be inferred that participant two had the lowest scores throughout the study, possibly an indication of his physical disability.

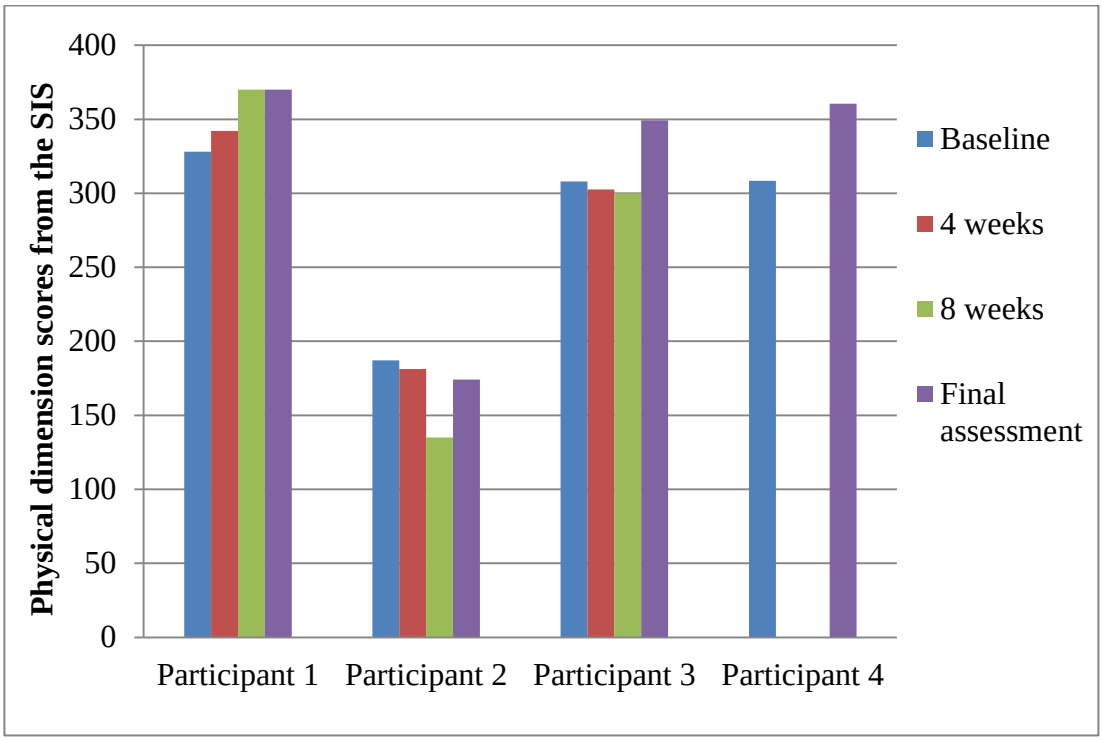

Figure 7.29: Comparison of the physical dimension scores of the SIS between all participants across data collection points

Key: Baseline data represents the average baseline for all participants excluding participant three who had only one baseline assessment; final assessment was conducted at the end of intervention (12 weeks) for participant one and two, as follow-up assessment after 16 weeks for participant three, and as follow-up assessment after 12 weeks for participant four; participant four did not have assessments at four and eight weeks.

Based on normative values established by Duncan et al. (2002) in the stroke population, all participants in the current study had three or more domains with scores within the normative range at baseline. A MDC for this measure for this population was not available.

The MCID for this measure has been established by Lin et al. (2010b) for four domains i.e. strength (a change of 9.2 points), ADL/IADL (a change of 5.9 points), mobility (a

change of 4.5 points), and hand function (a change of 17.8 points). On considering the change in SIS scores between baseline and final assessment, participant one demonstrated a change in strength that exceeded the MCID (a change of 21.9 points) while participant three demonstrated such changes in the domains of ADL/IADL, mobility, and hand function (changes of 10, 11.1, and 20 points respectively). Participant four's change for the domain of mobility (a change of 8.8 points) was higher than the MCID established. Participant two had a decrease of 11.5 points in the domain of ADL/IADL which was higher than the MCID, suggesting that this participant clinically declined in this domain.

7.5.7.7. Summary of synthesis of quantitative data

Overall, participant one showed improvements in all the outcome measures, while participant two had either declines or the lowest scores on the outcome measures. Issues raised and discussed in the goal setting discussions were most often reflected in the outcome measures. For example, participant two always identified problems with the strength of his affected side and this was reflected in the SIS scores. The slow walking speeds (from the 10MWT), and the high TUG test scores may also be an indication of this. Similarly, participant three had personal life changes, which were again reflected in the SIS scores through the emotion and social participation domains. However, few discrepancies were seen, especially with the activPAL™. For example, participant three felt his physical activity levels had dropped, however, the activPAL™ measures showed an improvement between baseline and final assessments. Similarly, participant two indicated that he had improved his walking distance, however, the activPAL™ showed decline between baseline and final visit.

The above findings suggest that a difference may exist between findings from objective measures and subjective measures. However, further exploration is needed before any firm conclusions are made due to the small numbers involved in this study. Nevertheless, it emphasises that both objective and subjective measures are needed as

these may highlight various aspects of an individual and the different influences from a complex intervention.

7.5.8. **Synthesis of experiences of goal setting**

The theme structures from the individual participants were integrated in an attempt to identify similarities and differences between the participants and this was used to provide a summary of the views and experiences of goal setting. The synthesised theme structure is presented as Figure 7.30.

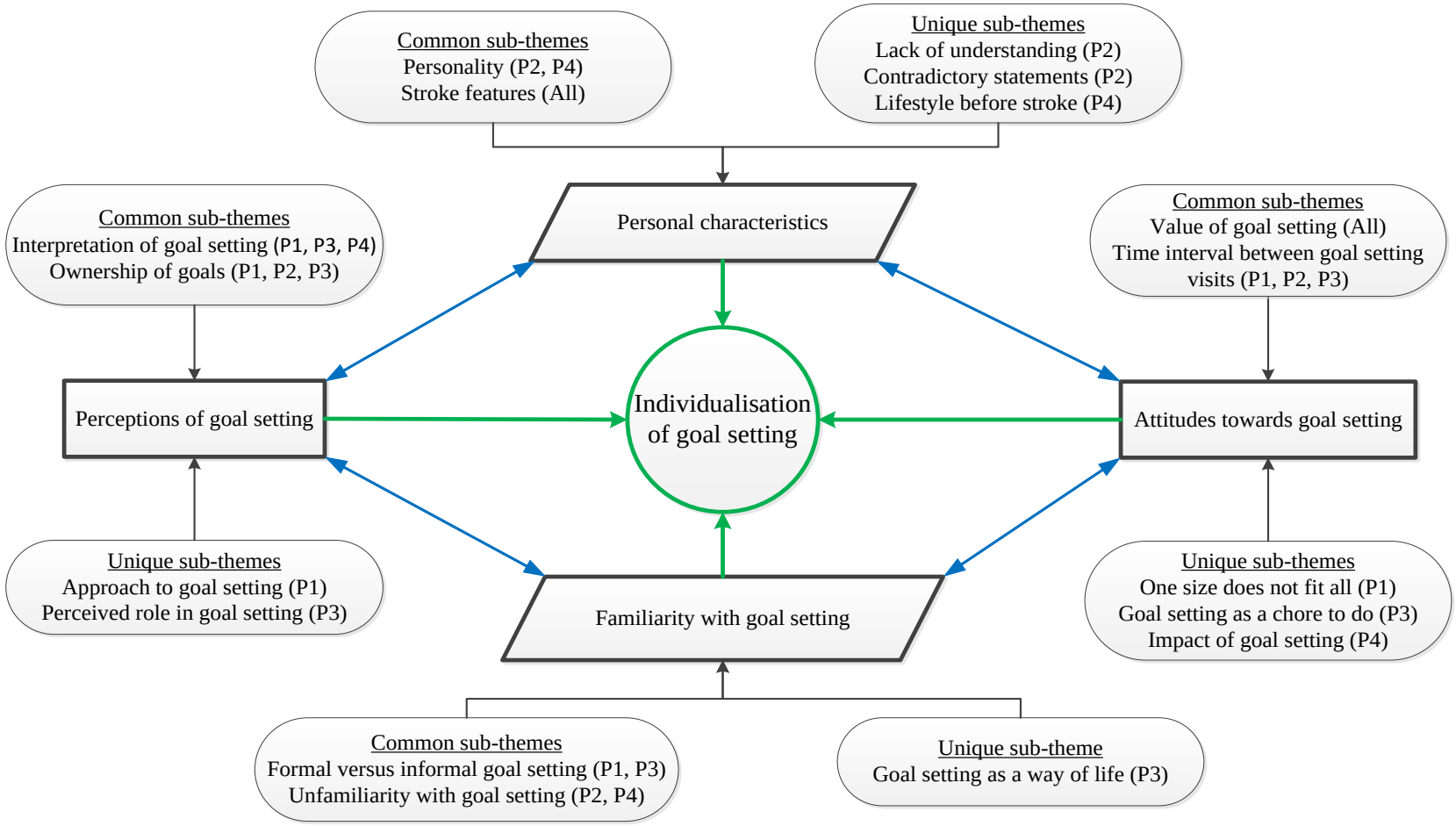

Figure 7.30: Synthesised theme structure representing overall experiences of goal setting

All four participants had perceptions of goal setting and attitudes towards goal setting as the main themes. However, the sub-themes that contributed to the main themes differed between participants. These common and unique sub-themes have been differentiated in Figure 7.30. Two linking themes were identified, namely: familiarity with goal setting and personal characteristics. For participants two and four, 'unfamiliarity with goal setting' was identified only as a sub-theme to explain perceptions of goal setting during individual analysis. However, when analysing the data for a group, it appeared to fit in with the linking theme of 'familiarity with goal setting' and hence was considered here. Similarly, personal characteristics of participants one and three were not included as linking themes in the individual analysis. References made to personal characteristics were considered within the attitudes towards goal setting for participant one and within perceptions of goal setting for participant three. However, during group analysis, it appeared appropriate to include it as a linking theme.

All the themes and sub-themes have been explained with illustrative quotes in the individual case studies. On synthesis, similarities were identified in the experiences between participants. From this exploration and synthesis, an overarching theme - 'individualisation of goal setting' - was created and this explained the overall views and experiences of participants relating to goal setting. The following sub-sections will discuss these in detail.

7.5.8.1. Similarities in experiences

In more than one way, participants one and three had similar views and experiences, while participants two and four were similar. Participants one and three had previous experience with goal setting, although not in a formal way as employed in the study. This previous experience appeared to make goal setting more relevant to them than to participants two and four, for whom goal setting was a new experience. Both participants one and three showed better understanding of goal setting than the other two participants. These similarities may explain the more positive experience described by

participants one and three on comparison with participants two and four. Although positive, they were quite critical of certain aspects of the goal setting method, such as the workbook. This again reflects their understanding of goal setting and what they require for successful progression towards their goals.

7.5.8.2. Individualisation of goal setting

Although some similarities were evident between the participants' experiences, the presence of unique sub-themes for all the themes highlighted the individualisation required within goal setting, hence this overarching theme. Individuality was apparent in the participants' willingness to participate in goal setting, and also their understanding of abilities required for participation. Further, all four participants were individuals with different personalities and varied lifestyles. These appeared to be the determining factors regarding whether they felt goal setting was relevant to them or not.

7.6. Discussion

The findings of the study are discussed first in line with the proposed aims, followed by a general discussion of the findings, the strengths and limitations of the study, and implications and recommendations for both research and practice.

7.6.1. Feasibility of the person-centred goal setting intervention

The first aim of the study was to determine the feasibility of the person-centred goal setting intervention for exercise after stroke that was designed and piloted in the previous two chapters. The proposed plan of conducting goal setting for participants who were involved in an exercise programme was only partially achieved in this study. Only two participants (participants one and three) were involved in the EaS service, of which participant three had to withdraw from the EaS programme due to personal relocation. Participant one was involved in the mainstream sessions, which were not

supervised, structured, or stroke-specific. The other two participants (participants two and four) were not involved in any exercise programme. Therefore, the feasibility of goal setting should be considered only in the light of general physical activity, rather than in conjunction with the exercise programme as originally planned. As stated in the aims (section 7.2), feasibility in this context included the following: recruitment from the exercise after stroke setting; setting/creating goals in this population; acceptability of the goal setting process by the participants; delivery of the goal setting intervention by the researcher; adverse effects from the intervention; participants' compliance with the intervention and participants' compliance with the study. Each of these elements is discussed in the following sub-sections.

7.6.1.1. Recruitment

Based on the number of participants who were contacted by the researcher for participation in the study, recruitment to this study was 62.5% (i.e. 5 out of 8 participants). However, one person could not be located after the first appointment, and one person opted out of the main intervention mid-way (although he participated in the outcome measures assessment). This resulted in a low study completion of 37.5% (i.e. only three participants completed the study) and a high non-completion of 40%. Moreover, the planned number of participants (ten participants) could not be recruited, even when the period of recruitment was extended and extra recruitment strategies were implemented. During the entire recruitment period of nine months, only five participants were recruited. This level of recruitment would not be suitable if a larger trial is planned in the future with the same population, and therefore further methods to improve recruitment should be considered.

The low number of referrals to the EaS service, discussed by the EaS authorities, could be cited as a reason for the low recruitment. However, it should be noted that the exact number of referrals was not disclosed to the researcher due to data protection issues. Hence the ratio of the number of people approached, to the number who agreed to be

contacted by the researcher could not be calculated. This information would have been helpful to identify the number of people that would need to be approached in order to achieve a targeted sample size for a future trial.

Gaps in communication between the researcher and the authorities of the EaS service may have also affected recruitment. During the period of recruitment, there were three staff changes which introduced a communication gap. The researcher had to repeatedly introduce the study and explain to the relevant person their role in recruitment to the study. At all times, the researcher provided all information regarding the study and was also available for a meeting in person. The researcher maintained regular contact with the relevant personnel through email and sent reminders every fortnight about the study. However, unforeseen organisational changes within the EaS service increased the workload of the person responsible for recruitment to this study and this was often cited as a reason for the delay in responding to the researcher. Moreover, the researcher was not based at the recruitment site and this raised issues regarding the release of some data from the recruitment source. For a larger trial, a dedicated person should be assigned for the role of recruiting participants and appropriate ethical procedures should be in place to ensure that this person would have access to all records. This would help to overcome the above mentioned difficulties with recruitment.

It should be acknowledged that only one recruitment source was used in this study. This may have resulted in low numbers. During the design of the study, the EaS authorities had agreed that recruiting ten participants for the study would be feasible based on the number of participants who were involved in the EaS service at that point in time, however, no exact numbers were disclosed. Therefore, the option of recruiting from another service was not considered. In hindsight, this would have increased the chances of conducting a cohort study as planned. For the future, it is recommended that multiple recruitment sites/sources should be identified to recruit a higher number of participants.

However, the exercise intervention provided within these services should be similar, or comparable, for standardisation purposes.

Although participants were recruited only from a single site for this study, a multiple recruitment strategy was followed. This was adopted to avoid losing any potential participants and improve recruitment. Interestingly, all eight potential participants were referred by the Physiotherapists of the local NHS. This raises a question as to whether a difference in perception regarding research exists between the NHS and the leisure industry. Moreover, it is not known whether any participants were referred to the EaS service from other referrers, such as Stroke Nurses and G.Ps., during this period, to be considered for recruitment.

7.6.1.2. Compliance with the study

All three participants who completed the study felt that the timings involved within the study were appropriate. Although these numbers are small, it can be cautiously concluded that similar time frames could be used in related trials in the future.

7.6.1.3. Delivery of the goal setting intervention and adverse effects

The person-centred goal setting intervention and the study were carried out without any adverse events. The researcher was able to deliver the intervention to all four participants. Hence, it could be cautiously concluded that the delivery of the intervention was feasible, keeping the low number of participants involved in consideration. However, one participant opted out of the intervention, citing lack of relevance as reason. It was not clear whether the participant's issue with memory was also a reason for withdrawal. During the study, the researcher constantly reminded the participant of the purpose of the study and what was expected from the participant in terms of goal setting. The goal setting workbook was also expected to help people with cognitive problems, as all the information was provided in writing which could serve as a

reminder of the goals and the progress they were making. However, participant four raised a valid point during the interview that remembering to pick up the workbook was an issue in itself. This highlighted that more measures need to be in place to ensure that participants with cognitive problems are well supported in goal setting. One possibility could be the inclusion of a telephone conversation mid-way between the visits. This would mean that the researcher had contact with the participant every two to three weeks. However, this raises feasibility issues of time and resources and will need to be explored further.

7.6.1.4. Acceptability of the goal setting intervention

Feasibility in terms of acceptability of the intervention was mixed. No negative comments were made by any of the participants on the goal setting method employed in the study, or about the manner in which it was delivered by the researcher. The goal setting workbook, however, received some critical comments. Participant one felt that the workbook was "repetitive", and participant three described it as "annoying", again due to repetitiveness and the time involved in completing the workbook. However, it must be recognised that both of these participants functioned at a high level, both physically and mentally, in comparison with the other two participants (e.g. high SSEQ scores for participant one and three, low physical dimension scores on the SIS and low self-efficacy scores on the SSEQ for participant two, and low scores on the memory domain of the SIS for participant four). The workbook was designed to maximise participant involvement in goal setting, provide them with a sense of ownership of goals, remind them of their goals, record their progress, and provide feedback. Although critical about the workbook, both these participants recognised the value of writing down the goals and having a measure in place to identify goal achievement or non-achievement. For the current study, the content of the workbook was the same every month. Therefore, exploration is needed whether the repetitiveness in the workbook could be reduced while also achieving all of its objectives. One possibility could be asking high functioning participants to write down only monthly goals instead of weekly

goals during the follow-up visits. This may reduce the repetitiveness while also adopting the ‘less is more’ strategy suggested by participant three.

In line with the reasoning behind the design of the workbook, it would appear that the workbook could have benefitted participants two and four. However, it was felt that both these participants did not make full use of the workbook, as was evident in the interviews. Participant four identified his problems with memory as one of the one of the reasons for not using the workbook. Participant two completed the workbook, and stated it was useful. However, how it was useful was not evident from the interview nor was reflected in any of the outcome measures. Moreover, his lack of understanding of the whole concept was raised throughout, which could be applied to the workbook as well.

Patient related barriers to goal setting, such as lack of understanding, were considered during intervention development and the recommendation of providing patient education on goal setting was addressed within the intervention. Accordingly, the meaning of person-centred goal setting, and its possible benefits were explained to all participants at the start of the study and reiterated throughout. Further, the goal setting workbook contained all this information in writing. A pictorial representation of how working towards a short-term goal would help in achieving a long-term goal was also included in the goal setting workbook. In spite of all these efforts, the interview with participant two suggested that he did not understand the concept of goal setting and this could raise concerns about the content of patient education within the intervention. However, this only occurred with one participant, while the remaining three participants were able to provide accurate interpretations of goal setting. The cognitive problems of this participant may have contributed to the lack of understanding; however, other methods of education could be explored to improve understanding of goal setting.

7.6.2. **Experiences of goal setting**

Another aim of the study was to qualitatively explore the participants' experiences of goal setting. Perceptions of goal setting, and attitudes towards goal setting emerged as the main themes, while familiarity with goal setting, and personal characteristics emerged as linking themes. Synthesis of the findings led to the creation of an overarching theme called 'individualisation of goal setting'. Some of these themes were identified by other researchers as well (Conneeley 2004, Holliday et al. 2007a, Young et al. 2008, Scobbie et al. 2013). Participants who were involved in goal setting in previous studies have expressed ownership of goals (Conneeley 2004, Holliday et al. 2007a, Young et al. 2008, Doig et al. 2009). In the present study, both participants one and three expressed ownership of goals and this could be related to their high involvement in goal setting. Conneeley (2004) further discussed that familiarity with the concept of goal setting may have led the majority of the participants in her study to have a clear idea of the reasoning behind the process of goal setting. Holliday et al. (2007a) had a sub-theme named 'past experiences' to explain how previous experience with goal setting influenced participants' current interpretations of goal setting. The relationship between familiarity with goal setting and interpretation of goal setting was also evident in the experiences of the participants in the current study. A recent study by Scobbie et al. (2013) linked the participants' beliefs regarding who was better placed to help them in their recovery (i.e. themselves or the professional) to the approaches adopted in goal setting (i.e. client-led or professional-led). This finding could be applied to the current study. Participants one and three believed that they were responsible for their recovery, and therefore took a lead role in goal setting by identifying their own goals. On the other hand, participant two looked to the researcher as an expert to suggest goals to aid in his recovery. Personal characteristics and level of neurological impairments, which were identified as influencing factors of goal setting in the current study, were also suggested by Holliday et al. (2007a).

Participants' familiarity with goal setting, their understanding of the process of goal setting, their personal circumstances, such as pre-stroke lifestyle and severity of stroke, appeared to influence their experiences, which highlighted the individualisation required within goal setting. Participants one and three were familiar with goal setting and had a much more positive experience of it than the other two participants. However, they felt they would have set goals even if they had not been involved in the study. Thus, the impact of the study on these two participants appeared to be low. On the other hand, for participants two and four, goal setting was a new experience. However, it was not considered to be relevant by one participant and was not completely understood by the other due to their personal characteristics. Hence, goal setting was not utilised by these two participants, and the impact of the study was, again, low. This raises a question as to who should receive goal setting and who will actually benefit from this intervention.

7.6.3. **Changes in outcome measures**

The third aim of the study was to analyse changes in the selected outcome measures over the data collection points. These outcome measures were selected in line with the aim of this programme of work. It was anticipated that the constructs measured in each of these outcome measures would reflect the behaviours targeted by the goal setting intervention, which included physical activity and physical function (e.g. walking and balance). Accordingly, issues raised and discussed during the goal setting conversations were reflected in the outcome measures (e.g. participant two's discussion of continuing the use of his walking stick to improve balance and to be able walk for a longer distance). Based on the MCID established in published literature for these measures, it appears that participants one and three improved on most of the measures. However, due to the nature of the study design and the small numbers involved, these changes cannot be attributed to the goal setting intervention, or the exercise classes, or both. Nevertheless, these changes highlight that the selected outcome measures may be responsive to change. Further, no difficulties were experienced in the application of any of these measures. Therefore, these measures could be suitable for use in similar trials of goal

setting in exercise after stroke. The inability to use all the measured variables of the activPAL™ needs to be addressed, for better use of this measurement tool. The possibility of the inclusion of an additional measure of self-efficacy has also been considered.

7.6.4. **Goal setting and participants' interests in physical activity**

The foundation of this programme of work was the belief that goal setting may function as a mediator to facilitate participation in physical activity. Since differences in response to goal setting were observed between individuals, reasons for this were explored. The relevance of goal setting to the participants was taken into consideration and this appeared to be influenced by the participants' interests in physical activity.

Participants one and three were interested in and wanted to improve their physical fitness, and therefore, goal setting within the context of physical activity may have appeared relevant to them. As part of improving their physical fitness, they also attended the EaS service. In contrast, for participants two and four, physical activity was not a priority. Neither of these participants attended the EaS service during the study. Participant four explained that he had a "sedate lifestyle", however, was "comfortable" with that and did not find it necessary to alter that lifestyle. His low level of physical activity was observed in the activPAL™ data, which showed that he spent more than 90% of his waking time in sitting/lying. Participant two, in his discussions with the researcher, shared that he had not been physically active pre-stroke. He also had other priorities in life during the course of the study and was not keen on physical activity. Moreover, his 10MWT and TUG test values showed that his mobility and balance were low. Therefore, it could be argued that it was more important for participants two and four to participate in physical activity and improve their physical fitness in comparison with participants one and three. In line with this, goal setting in the context of physical activity could have helped these participants (two and four) to change their physical activity behaviour, which was not found to be the case.

7.6.5. **Implications for practice and research**

Although only four participants were involved in this study, in-depth analyses of the findings have brought to the forefront various issues within goal setting. Based on the findings of this study, some aspects of feasibility of the goal setting intervention, such as the acceptability of the intervention, need to be addressed before this intervention can be translated into practice. Nevertheless, the more positive changes in the outcome measures over the course of the study for two participants who were interested in physical activity and engaged with the goal setting suggest that further investigation is warranted. The findings have also highlighted the individualisation required within goal setting (i.e. familiarity with goal setting and modifications within the workbook) and this should be taken into consideration for future goal setting practice.

The results and the discussions that followed have raised the following questions that will need to be considered and addressed in the future:

(i) How can recruitment to similar studies from the exercise after stroke setting be improved?

(ii) How can goal setting interventions be modified to suit and benefit participants with cognitive and/or communication problems?

(iii) Which sub-group of the population would benefit most from goal setting (e.g. in terms of familiarity with goal setting, interest in physical activity)?

(iv) Does a different sub-group of the population require a different approach to goal setting (e.g. modifications in the goal setting workbook based on the functional ability of the participants)?

7.6.6. **Strengths and limitations of the study**

The mixed method case series study design served both as the main strength and limitation of the study. Using mixed methods has led to a better understanding of the process and experiences of goal setting in this setting. Although the generalisability and

transferability of the findings were reduced due to the use of case studies, careful consideration of individual factors was possible. This again led to better understanding of the intervention under study.

A three-month follow-up as planned would have provided more information on the carry-over effect of goal setting, and the long-term physical activity behaviour of the population under study. However, as discussed in section 7.4.4, recruitment problems and time restrictions on the programme of work forced a change in the proposed plan and the follow-up assessment had to be dropped. Due to this, long-term changes could not be assessed.

Since no female participants were involved in the study, it is not known whether their involvement would have altered the study findings.

The small sample size was the major limitation of the quantitative part of the study. However, the data were analysed appropriately and the findings have been presented with caution. The researcher delivering the intervention also conducted the assessments and this may have introduced bias. However, the researcher adhered to standardised procedures throughout the study. The use of only selected measures of activPAL™ limited the opportunity to compare estimates of physical activity in terms of numbers of steps.

In relation to the qualitative part of the study, several strengths were evident. Having an independent person conduct the interviews increased the credibility of the findings. Moreover, various actions were taken to improve the rigour of the study, as outlined in Table 7.2. Since the number of participants was low, only analytical saturation was reached and not data saturation.

7.7. **Conclusion**

A mixed methods case study of four participants with stroke was conducted to evaluate the feasibility and user experiences of the goal setting intervention that was developed for this programme of work in the context of exercise after stroke, and to analyse the changes within the outcome measures over the course of the study. Some elements of feasibility, such as intervention delivery and compliance, were positive. However, findings regarding other elements of feasibility, such as acceptability of the intervention and the content were less positive, and raised various questions. Qualitative exploration of the participants' experiences brought out the importance of the individualisation required within goal setting and complemented the questions that were raised regarding feasibility. Participants' interest in physical activity, their familiarity with goal setting, and their level of functioning appeared to influence their perceptions of goal setting, and subsequently their involvement in goal setting. The outcome measures used in this study were found to be suitable for use in studies of goal setting for exercise after stroke.

To obtain a complete picture of goal setting in the field of exercise after stroke, it was not sufficient to only consider the views of the participants, but also the views and experiences of exercise professionals involved in this field regarding goal setting. A study conducted with this aim is presented in the next chapter.

8. STUDY FIVE: Experiences of exercise professionals regarding goal setting for exercise after stroke – A focus group study.

8.1. Introduction

A focus group study with the aim of exploring the perceptions and experiences of exercise professionals regarding goal setting was undertaken as the fifth study of this programme of work, and presented in this chapter. The background and rationale for the study are explained first, followed by the aims, and the methods employed. The results are presented next and discussed, followed by the conclusions.

8.2. Background and rationale

During the design of this programme of work, as part of feasibility assessment, the current study was planned to explore the experiences of exercise professionals involved in the previously selected EaS service regarding goal setting. It was anticipated that since participants for study four were to be recruited from this setting, these professionals would be ideally placed to discuss their perceptions and experiences of goal setting, and may be able to provide their views of the goal setting intervention under study. However, as explained in section 7.6.1.1, the service underwent several staff changes over the course of this programme of work. Hence, at the time of the initiation of the current study, only one REPS Level 4 exercise instructor who had completed the Exercise after Stroke Specialist Instructor Training Course was available. Therefore, it was not possible to conduct the study with the planned participants.

In the systematic review conducted as study one of this programme of work, none of the studies analysed the experiences of exercise professionals (refer to section 4.5.7). The professionals involved in these studies were Doctors, Nurses, Physiotherapists,

Occupational Therapists, and Speech and Language Therapists. A basic search in the 'Pubmed' database with the key words 'goal setting' and 'exercise professionals' OR 'exercise instructors' OR 'gym instructors' revealed no relevant study. The lack of evidence in this area highlighted the need for a study to explore views of exercise professionals regarding goal setting. Moreover, if the person-centred goal setting intervention were to be implemented in practice in the future, the exercise professionals would be responsible for its delivery, and therefore, it was deemed essential to capture their views in relation to goal setting and also explore their current goal setting practices, if any. It was also believed this would provide a more complete picture of goal setting in exercise after stroke. Therefore, it was decided to conduct the current study as planned, however, with exercise professionals from a different EaS service, as explained later in this chapter in section 8.4.3.

8.3. **Aims**

Therefore, the aims of this study were to explore the perceptions and experiences of exercise professionals involved in exercise after stroke in a leisure context regarding goal setting. The following two research questions were addressed in the study:

(i) What are the perceptions of exercise professionals involved in exercise after stroke regarding goal setting?

Perception was defined as, "the way in which something is regarded, understood, or interpreted" (Oxford University Press 2013).

(ii) What are the experiences of exercise professionals involved in exercise after stroke regarding goal setting?

8.4. **Methods**

8.4.1. **Study design**

To answer the above research questions, a qualitative research design was deemed appropriate. Since the focus of the study was on participant's views and experiences, a constructivist phenomenological approach was adopted (refer to section 7.3.2 for definition and further explanation).

Focus groups are semi-structured person-to-group interviews (Grbich 1999). Krueger and Casey (2000, p.5) define a focus group study as: "a carefully planned series of discussions to obtain perceptions on a defined area of interest in a permissive, non-threatening environment." The presence of multiple voices in a focus group brings forth not only individual views but also shared contexts (Palmer et al. 2010). This explicit use of group interaction to create data is a characteristic feature of this method of data collection (Morgan 1997). It was believed that a group discussion would bring to light a variety of perspectives on the subject of goal setting, and therefore, a focus group method of data collection was selected.

8.4.2. **Sampling**

Purposive sampling (i.e. recruiting participants on the basis of the aims and purpose of the study) is recommended for focus groups (Krueger and Casey 2000, Morgan 1997), and this was followed. Focus groups are used to explore people's shared perspectives on a research topic and therefore, random sampling would not suit this purpose (Morgan 1997). However, it was acknowledged that the use of purposive sampling would reduce the transferability of the findings (Morgan 1997). In line with purposive sampling and the research question, exercise professionals were recruited.

8.4.3. **Study population**

As explained in section 8.2, the current study could not be conducted with the planned participants, and an alternate source of recruitment had to be identified. Hence, another organisation in a different city in Scotland was approached. Within this organisation, two services (an Exercise Referral Scheme and a Group Exercise Scheme) were available for stroke survivors, and exercise professionals involved in these services were recruited for the current study. The two programmes are explained briefly next.

8.4.3.1. Exercise Referral Scheme

The Exercise Referral Scheme is a referral programme where an individual (healthy or any condition, including stroke) is referred by their GP, Practice Nurse or Physiotherapist with the aim of promoting, improving, and/or maintaining the individual's physical activity behaviour. Once referred, the individual is invited to attend an exercise consultation with an advisor (referred to as Referral Scheme Advisors (RSA) hereafter). A RSA is a qualified exercise professional who has completed the relevant training programme of the organisation. During the one hour initial consultation, the RSA obtains detailed information about the individual's exercise history, and in discussion with the individual, provides options to improve their physical activity. Goal setting also forms a part of this consultation. Based on the individual's condition and level of priority, he or she is referred to supervised gym sessions (with the RSA), the Group Exercise Scheme, walking programmes or weight management services. The individual can contact the RSA for further appointments.

8.4.3.2. Group Exercise Scheme

The Group Exercise Scheme is designed to build and maintain strength, co-ordination, endurance and flexibility. These classes are suitable for people with different physical abilities and medical conditions, including stroke, heart conditions, Parkinson's disease,

multiple sclerosis, osteoporosis and chronic obstructive pulmonary disease (COPD). These classes are conducted by qualified exercise professionals in community leisure centres and are referred as Group Exercise Instructors (GEI) hereafter. These professionals are self-employed. There are four levels of exercise classes, namely: Strength and Balance Class, Strength and Balance Circuit, Step In Circuit, and Step Up Circuit. The individual is referred to one of these classes based on their mobility and ability to participate in ADL. The classes are group sessions, with the number of participants and instructors determined by the level of the classes (as the level increases, the participant to instructor ratio decreases).

More information on the services emerged from the focus group discussions and is presented in the results later in this chapter (section 8.5).

8.4.4. **Ethics approval**

Approval was first obtained from the Director of Policy and Research of the organisation. This documentation was then used to obtain ethical approval from the Divisional Research Ethics committee of QMU (Appendix 14).

8.4.5. **Recruitment method**

The Physical and Outdoor Activities Officer of the selected organisation agreed to send the relevant participant information sheets to the exercise professionals of both the programmes (Appendix 15). A response letter and a self-addressed envelope were enclosed along with the participant information sheets. The exercise professionals were instructed to return the response form to the researcher to inform them of whether they were interested in participation and if so, their details and availability. The interested participants were contacted by the researcher to arrange a suitable date and time for the focus groups.

The RSAs were directly employed by the organisation, and did not require travel expenses or the time taken to participate in the study to be reimbursed. However, the GEIs were self-employed and were involved in the organisation indirectly. Therefore, their travel expenses and time spent in the study were reimbursed. This was made clear in the respective participant information sheets.

8.4.6. **Inclusion and exclusion criteria**

Exercise professionals delivering either the Exercise Referral Scheme or the Group Exercise Scheme and able to provide informed consent were eligible to take part in this study. Based on discussion with the relevant authorities, it was expected that all participants would have had experiences with working with stroke survivors. To confirm, a question about this was added to the response form that the participants had to complete to let the researcher know if they were interested in the study or not.

Participants who were not able to provide informed consent were excluded from the study.

8.4.7. **Number of focus groups**

Authors recommend that participants in a focus group should be homogeneous strangers and that a total of three to five focus groups with six to ten participants in each focus group should be conducted (Krueger and Casey 2000, Morgan 1997). Discussions were held with the relevant authorities of the organisation to identify the number of possible participants. Based on this, it was decided that four focus groups would be conducted in total: two with RSAs and two with GEIs. The plan was to include six to ten participants in each group, depending on the response rate. Conducting two focus groups with each sub-sample was expected to enable comparison between the sub-groups and within the sub-groups (Morgan 1997).

8.4.8. **Recruitment**

All thirteen RSAs were contacted and all of them agreed to participate (100%). However, one participant could not attend the focus group on the scheduled date due to sickness. Therefore, two focus groups were conducted with RSAs as planned, with six participants in each (92% participation rate).

All thirty-three GEIs were initially contacted by post with a three week time window to return the response forms. However, only six (18%) showed interest. The rest of the instructors did not return the response form and therefore, the reasons for non-interest were not known. Due to the low response, all the other participants were again contacted by post as a reminder and were asked to return the response form within three weeks. No further response was obtained. After discussion with the relevant authorities at the organisation, all the GEIs were again contacted by email, if provided, or by post. The authorities were conducting a training day around that time and they agreed to introduce the study to the GEIs during that day. None of these strategies yielded the expected results and no more responses were obtained. Hence, only one focus group was organised for this sub-group. Since these instructors are self-employed and have different working patterns, a date and time suitable for all six participants could not be arranged, even three months in advance. The time restrictions on the programme of work did not allow for further flexibility. In the end, a date and time that was suitable for four participants was arranged. One participant cancelled the day before the focus group due to personal reasons. Therefore, only one focus group was conducted with GEI, with only three participants (participation rate of 9%).

8.4.9. **Preparation of the topic guide**

A clear and structured topic guide was developed for this study and is included as Appendix 16. The detailed guidance provided by Morgan (1997) and Kreuger and Casey (2000) was used in the development of the topic guide. Accordingly, an opening

question, an introductory question, a transition question, several key questions and an ending question were developed. For each key question, a number of relevant probing questions were formulated. The key questions that are presented below were decided based on the review of literature on goal setting (chapter 4) and focussed on the following topics:

(i) Meaning of the term 'goal setting'.

(ii) If and how goal setting is practised in their setting.

(iii) Motivators and barriers to goal setting.

(iv) Perceived usefulness (or not) of goal setting.

The topic guide was similar for both the sub-groups, excluding probing questions regarding the passing on of goals from the RSA to GEI. The topic guide was then reviewed by experienced qualitative researchers within the team (CB and MD) and finalised. This version was sent to the authorities of the organisation for review and they suggested no changes.

8.4.10. **Moderator – skills and responsibilities**

The researcher (TS) planned to moderate all the focus groups to avoid different influences on both the data collection and data analysis processes. Since the researcher was a beginner in qualitative research, she undertook some training from an experienced qualitative researcher (CB) within the team. As part of the training, she also participated as a co-moderator in two focus groups, moderated by the above researcher (CB). These focus groups were conducted as part of another research project and had no connection with the current study. Involvement in the focus groups as a co-moderator helped the researcher understand the nuances of focus group design and skills of moderation. The researcher was also involved in the planning and set-up of the focus group, thereby gaining experience to be utilised for the present study.

It has been recommended that the moderator should have a mild, yet unobtrusive, control over the discussion of the group (Krueger and Casey 2000). In this study, the

role of the moderator was to ask key questions to initiate discussion; ask probing questions to widen discussion; ask for clarifications; and provide a summary of the discussion. Otherwise, the moderator aimed not to participate in the discussion or disrupt the discussion.

8.4.11. **Co-moderator**

An experienced researcher from the supervisory team (FvW) acted as a co-moderator for all the focus groups. The role of the co-moderator was to help in the setting-up of the room and equipment; to record the seating plan; to take notes on the approximate order of speech, the main points made, and the body language (e.g. nodding as in agreement); and ask any missing or follow-up questions at the end.

8.4.12. **Study setting**

The focus groups were conducted in one of the meeting rooms in the Organisation's main campus. This room provided the required privacy.

8.4.13. **Equipment**

The following equipment was used in this study:

(1) Digital voice recorder (Olympus DS-2600 and Olympus WS-650S)
(2) Digital camcorder (Sony® Hybrid model no: DCR-DVD 110E)
(3) DVD's (Fujifilm DVD-R)
(4) Digital stop-watch (TM20)
(5) Flip-charts.

8.4.14. **Study procedure**

The following procedure was followed for all the focus groups.

Before the participants arrived, the room was setup with the correct number of chairs around a square table. It was ensured that the arrangements were such that the moderator was able to see all the participants and the participants were able to see each other. To ensure that no data were missed due to technical problems, it was decided that two digital voice recorders would be used. In addition, it was decided that video recording of the whole discussion on a digital DVD camcorder would be conducted, to enable the researcher to identify the speakers and pick up any important non-verbal communication. The digital camcorder and the digital voice recorders were checked and positioned appropriately to ensure accurate recording and to avoid missing any data. The ground rules and the main topics of discussion were written on a flip chart and positioned for all the participants to view. A blank flip chart was also pinned to the wall to note down important topics that the participants might want to discuss, but which were not directly relevant to the discussion topic. This was to ensure that the discussion did not deviate from the topic of focus, while at the same time emphasising to the participant that their views were being taken into consideration and that the topic would be discussed at the end of the focus group.

Once the participants arrived, they were welcomed and provided with name badges. The participant information sheet was provided and any questions answered. The participants were then asked to sign the consent form.

The moderator started the focus group with introductions. The participants were informed that the focus group discussion would last approximately for an hour. The roles of moderator and co-moderator, outlined in sections 8.4.10 and 8.4.11, were explained to the participants. The ground rules were established, with emphasis on respecting each other's privacy and maintaining confidentiality. A brief introduction to

the project and the need for the focus group was presented. The main topics for discussion (sub-section 8.4.9) were highlighted. The participants were also informed that any other issues out with the topic of discussion would be taken into account and discussed at the end of the focus group.

The voice and video recorders were switched on, along with the stop-watch. The moderator then started the discussion with the use of the topic guide questions. Once all questions were discussed, the co-moderator was asked if any information required clarification or further questioning. The participants were then asked to consider everything discussed and highlight their individual key message.

The participants were informed that the discussion would be transcribed and a one page summary of the key findings would be sent to them for verification. The audio and video recorders were then switched off.

The moderator and co-moderator held a debriefing session to discuss the key messages. The moderator also used this time to reflect on her questioning styles and on whether this could have had any influences on the participants' responses. These reflections were recorded in writing (reflective journal) to be referred to during analysis.

8.4.15. **Transcription and participant verification**

The focus group discussions were transcribed from the video recordings. The audio recordings were used if anything was unclear in the video recordings. The co-moderator notes were inserted where appropriate. This verbatim record of the discussion was used for analysis.

A summary of key statements was created and sent to all the participants for verification. All participants responded and no changes were suggested.

8.4.16. **Data analysis**

The data were analysed using Interpretative Phenomenological Analysis (IPA). This method of analysis follows phenomenological theory and hence its use in this study was aligned with the study framework. The aim of IPA is to explore how people ascribe meaning to their experiences of a given phenomenon, in a particular context (Palmer et al. 2010). In IPA, the researcher attempts to interpret and explain the participant's experiences by engaging in an analytic process (Smith et al. 1997).

Although IPA is commonly used for individual interviews, it has only occasionally been used to analyse focus group data (Tomkins and Eatough 2010). In a focus group, the experiential account of a phenomenon is not only shaped by one's personal experience, but could also be influenced by the shared experiences of other participants. Therefore, it has been recommended that the group interactions and how meanings were changed and/or evolved during the discussion should be taken into account in order to obtain a thorough analysis (Palmer et al. 2010). Hence in this study, whilst following the systematic process of IPA [i.e. identifying similar ideas, creating themes, exploring the possible relationships between the themes as evident from the text, developing theory to explain the experiences] (Smith et al. 1999), the other features such as positionality, roles and relationships, and language were also considered in the formulation of themes and connections, as proposed by Palmer et al. (2010).

The data analysis process began by reading the first transcript a number of times in order to understand the discussion. While reading, initial ideas from the text were noted on one side of the margin, such as summaries of statements, associations, or preliminary interpretations. The next step was to identify emerging sub-themes from the initial ideas and code these for reference purposes. Connections between the sub-themes were then explored to create themes. Each theme was defined and coded for reference purposes. The themes and connections were checked again against the transcript to ensure that

they provided an accurate reflection of the data. The analysis of a text unit from focus group one is presented in Table 8.1 as an example to show the different steps followed.

Table 8.1: Example of data analysis (study five)

Text	Initial ideas	Sub-themes	Themes	Connections
[28]**Frank (RSA):** Certainly goal setting in our client group, be it main stream clients or clients post-stroke, it is flexible or changeable, because they may go on to other classes we recommend, but the time may not suit them or they may go along but do not enjoy it because the client group is too old or something like that or they do not like the gym because it costs too much money and so we are tied by these sorts of constraints as well within goal setting.	Goal setting process flexible/changeable	Flexibility in goal setting;	Goal setting approaches;	In this text unit, The participant connected the flexibility of goal setting to the challenges that were related to the client. Hence these themes goal setting approaches and challenges to goal setting were interpreted to be linked.
	Time - client	Client-related challenges /constraints	Challenges to goal setting	
	Not enjoy - client			
	Not like the activity - client			
	Cost - client			

Next, the interactional component of the focus group was analysed. For this, the role played by the moderator and the other participants in shaping up an individual's view was identified. Any agreements, disagreements, or alternative views expressed were noted. How the individual viewed his/her professional role and what references were made to the organisation/service were then considered. The individual's use of language (pattern, in what context was it used, how and/or why it was being used) was also explored. As the next step, the themes that were created first were adapted to reflect the interactional components. Analysis continued until no new theme was identified.

The same procedure was repeated for all the focus groups. The themes of each focus group were then considered and a consolidated list of themes was created. Finally, relationships and/or connections between the themes were analysed to form an overarching theme to explain the perceptions and experiences of exercise professionals regarding goal setting. The relationships between the themes were determined in most cases by connections that appeared in the data (e.g. use of terms such as 'because', 'due to', 'so'). In some cases, the flow of data suggested a connection and therefore, these were interpreted as relationships. In the results section, where the relationships are presented, it has been made clear whether these were apparent in the text or interpreted by the researcher. The data analysis procedure is summarised in Figure 8.1.

Since the researcher was new to qualitative research, and to enhance rigour, an experienced qualitative researcher from the team (MD) analysed the data independently to create sub-themes. The sub-themes were compared and no discrepancies were identified. The principal researcher then formulated the themes and the overarching theme, which was verified and agreed by the second researcher (MD). The researcher kept notes on the decisions made at each stage and the justifications for these as part of audit trail, to ensure transparency of the process.

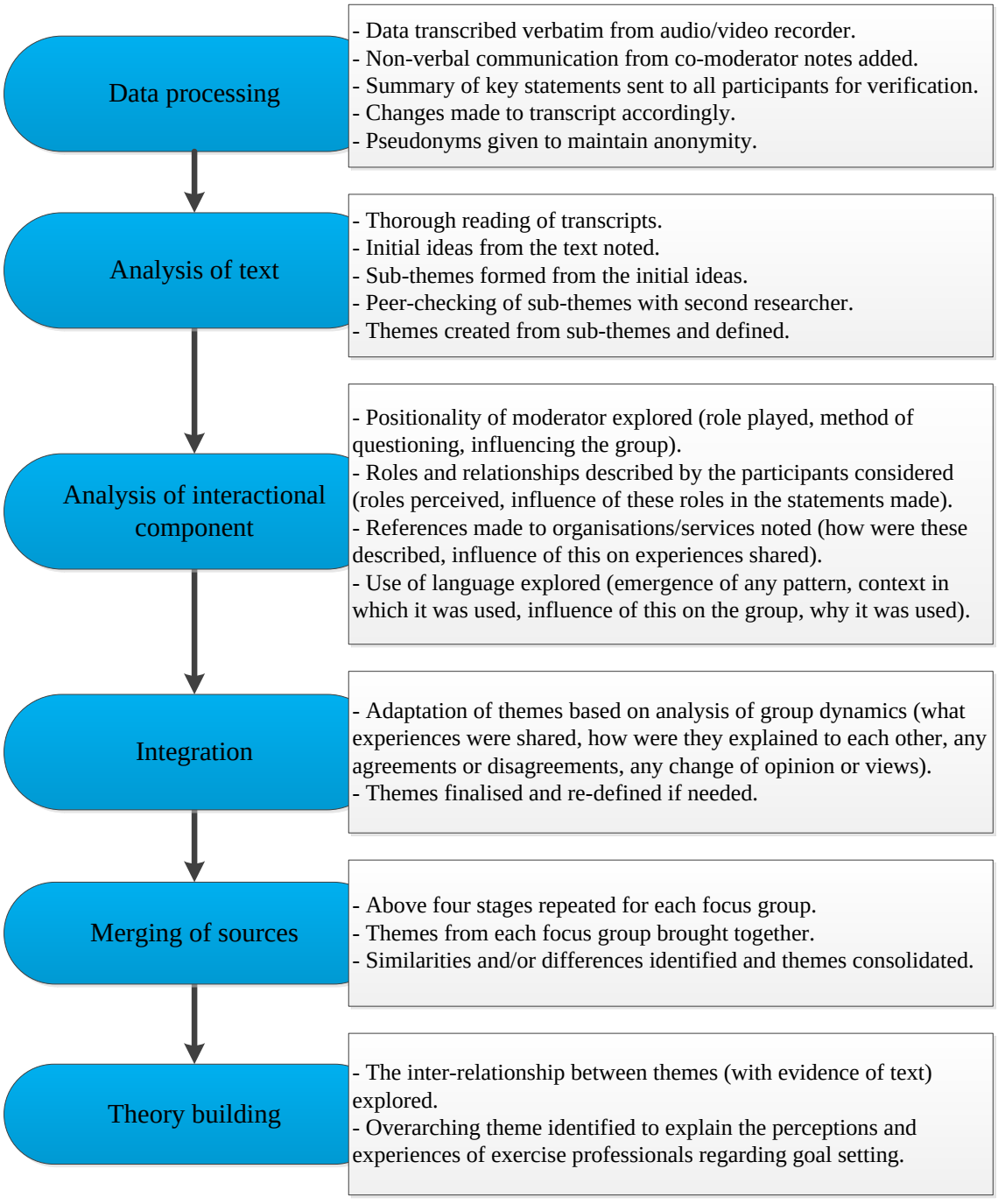

Figure 8.1: Data analysis process (study five)

8.4.17. **Rigour in qualitative research**

Similar criteria that were followed for the qualitative strand of study four was followed in the current study to ensure rigour (refer to chapter 7 section 7.4.13 for details). The criteria and the actions taken to ensure the criteria are met are outlined in Table 8.2.

Table 8.2: 'Rigour' criteria and actions taken to ensure rigour (study five)

Criterion	Action taken to ensure criterion was met
Triangulation	Two sub-groups of the sample population were included to be able to analyse the differences and similarities between them. A second researcher (MD) was involved to check the data analysis process.
Member checking	Key statements were summarised within a week of the focus group and sent to all the participants for verification. All participants agreed with the summary, with no additional comments.
Credibility	A reflective approach was adopted by keeping a journal of reflection and a note on the preconceptions and ideas of the researcher that may have introduced bias. The actions undertaken to ensure triangulation and member checking were also related to credibility.
Transferability	The participants and the settings were described clearly and in detail to enable valid conclusions on the generalisability of the results.
Dependability	An audit trail was maintained as evidence of the decisions made throughout the study. Peer review during the data analysis stage reduced individual bias.
Confirmability	Moderator reflective journal, participant verification, peer review, and audit trail were undertaken.

8.5. **Results**

Two focus groups (n=6 in each) with RSAs and one focus group (n=3) with GEIs were conducted in the months of October and November 2012. The focus groups with the RSAs were held on the same day, with a 30 minute interval, while the focus group with the GEIs was conducted later, on a different day. The characteristics of each group are presented in Table 8.3. The individual details of the participants have not been provided to prevent breach of confidentiality as it may be possible to identify participants by combining personal data due to the small pool of potential participants. The seating arrangement for each focus group and the transcripts are attached as an electronic appendix (CD-ROM). Although experience with stroke was not an inclusion criterion, all participants had experience with stroke. The lengths of the focus groups were between 45 minutes and 55 minutes each.

Table 8.3: Sample characteristics of the focus group

Focus group number	Number of participants	Pseudonyms	Participants' occupation	Mean age in years [range]	Male : Female ratio	Mean duration in current job in months [range]
1	6	Amy, Beth, Chris, Dan, Frank, Gary	Referral Scheme Advisor	32.8 ± 4.5 years [27-38]	4 male : 2 female	25 ± 23.1 months [2-52]
2	6	Helen, Jema, Kate, Lee, Mandy, Neal	Referral Scheme Advisor	30.8 ± 4.9 years [23-36]	2 male : 4 female	39.7 ± 26.5 months [2-69]
3	3	Ria, Linda, Tom	Group Exercise Instructor	45.7 ± 3.1 years [43-49]	1 male : 2 female	116 ± 36.7 months [84-156]

Following data analysis, one descriptive theme and five interpretive themes were created. The descriptive theme explained the goal setting procedure employed by the participants in their day-to-day practice. The interpretive themes included: perceptions of goal setting, roles of the participants in their respective services, goal setting approaches, challenges to goal setting, and strategies and suggestions for more effective goal setting (Figure 8.2). These themes and the contributing sub-themes are explained first, with illustrative quotations. The interactional elements of the focus group are discussed next. Finally, the integration of themes, along with the group interaction that led to development of theory (main message) is presented.

Where possible, quotes are integrated within the text. In other cases, the quotes are presented as a table and signposted within the text. For each quote, the name of the participant, their job title (i.e. RSA or GEI), and the focus group in which they took part (i.e. 1, 2, or 3) are provided to ensure transparency of findings. The paragraph number (text unit) is also provided as a superscript in all quotes to be able to identify the context of the discussion. In some cases, minor editing of extracts was made to improve clarity. These amendments are provided in square brackets. The participants in all the focus groups identified their service users as ‘clients’ and hence, this term is used throughout this chapter to denote service users.

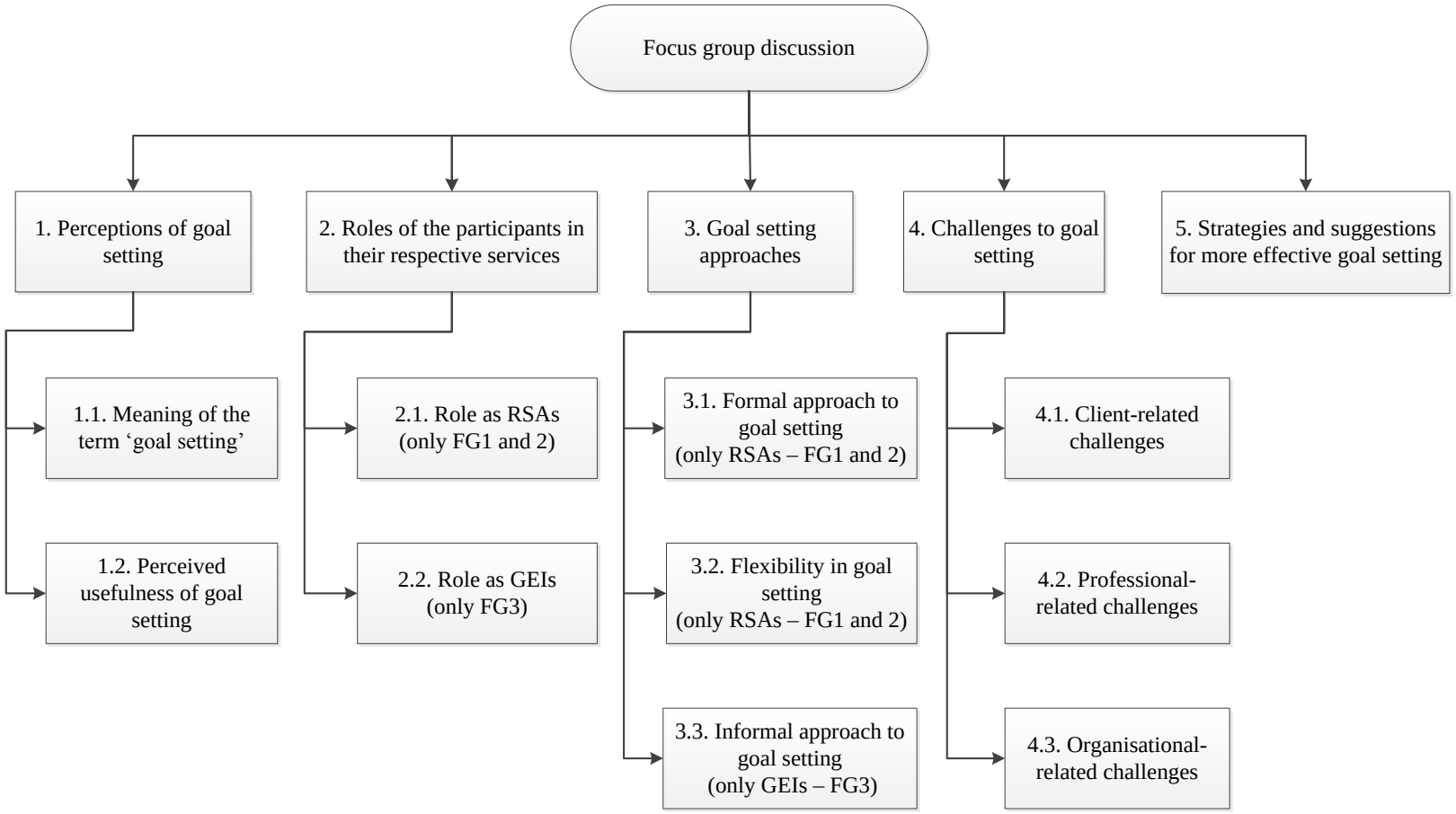

Figure 8.2: Structure of the interpretive themes from the focus groups

Key: RSAs – Referral Scheme Advisors; GEIs – Group Exercise Instructors.

8.5.1. **Goal setting procedures**

In order to understand and interpret the participants' experiences of goal setting, it was important to gain information on how goal setting is conducted in their day-to-day practice. The information collected was synthesised as a descriptive theme and is presented here. All participants agreed that goal setting was part of their everyday practice, although their approaches to goal setting differed. These approaches have been integrated as an interpretive theme and are explained later (section 8.5.3). As part of the goal setting procedures, the participants talked about the principles involved in goal setting, the types of goals they set, how they reviewed goals and the specifics of goal setting for clients with stroke. These are discussed in the following sub-sections.

8.5.1.1. Principles of goal setting

All participants acknowledged that goal setting should be done on "SMART" (Frank RSA Focus group (FG) 1[17], Dan RSA FG1[121], Ria GEI FG3[193]) or "SMARTER" principles (Kate RSA FG2[17], Jema RSA FG2[84]). When asked to expand the abbreviation, Neal and Helen (RSA FG2[83]) answered "specific, measurable, achievable, realistic, time limited". To expand SMARTER, "efficient" (Kate RSA FG2[86]) and "recorded" (Neal RSA FG2[85]) were added by the participants.

However, deviations from these principles were noted by Helen (RSA FG2[89]) who said that, "I do not write mine in that format. I … write what they say. If they say they want to come to the gym twice a week, then I would write gym twice a week … If they are more specific I will put in what they say". She also provided the following reason for this deviation: "I would not necessarily put them in such a standard format because you want them to be able to read it and look at it and say 'oh that is what I am going to do or that is what I said I will do'. Basically, if you put it down in a kind of more structured format, they might wonder why … So you do write what they are aiming for and you write what their progression is throughout" (Helen RSA FG2[89]). Neal (RSA FG2[111]),

from the same focus group, added that, "… we sometimes might get a little bit stuck on to writing down the specific, measurable goals; sometimes the goal for that person may be just turning up next week to do something … So I think it varies in terms of the importance really."

8.5.1.2. Types of goals

The participants also discussed the types of goals they set. Both "structured exercise and lifestyle [goals]" (Helen RSA FG2[55]) were set as goals. All participants emphasised the importance of the goals being 'functional' and 'personalised', as seen in the four excerpts in Table 8.4.

Table 8.4: Illustrative quotes to demonstrate the types of goals that are set

FG2 (RSA)
[40]**Jema:** …. very often, I find that goal setting is not around structural activity, it can be generalised day to day activity as well, like chair based activity, activity around the house, taking the dog for a walk, obviously focussing on structured activity.
[99]**Helen:** Sometimes we will set the simplest goals like walk to your car, rather than getting too [complex]. Like for a person using a wheelchair for example, they do not necessarily have to use [it]. Then you may say, right, let us try and leave your wheelchair at the house and get to the car. So it can be really, really, small goals. It is not always going to the gym and swimming. It is sometimes the most basic things.
FG3 (GEI)
[79]**Tom:** … especially if it [is] everyday life things like walking down to a local newspaper to get a newspaper…
[83]**Ria:** It is very much functional capacity and you have to relate that with whatever you are doing. For example: sit-to-stand will help you when getting up from a chair, when you are on [a] seat, when you can get into a bus, It will help you with functional activities … for somebody who's had a stroke that is talking their language. It means something to them.

8.5.1.3. Goal review and follow-up

On discussion about goal review and follow-up, the participants were in agreement that the time frames set varied between individuals. They stated that goals were reviewed at follow-up and modified as needed. However, the RSAs reported that goals decided during the consultations were not shared with GEIs even if the client was referred to the Group Exercise Scheme, for reasons of maintaining confidentiality. As Chris (RSA FG1[74]) pointed out "we may pass the client on [to] exercise in their environment. But we would not inform them or anyone else of their [goals], [for] confidentiality … Agreed goals that we have made with the clients, it has got to stay between them and us". Lee (RSA[67]) in FG2 made a similar comment that, "with regards to the … classes, that will be one of the goals we set for the patients, rather than sending the rest of the goals to the … instructors. The goals will be to attend that [group exercise] class once a week and then there will be another goal on top of that, depending on the patient." GEIs discussed this along the same lines, that they do not know the goals that are set by the RSAs and do not follow them through. With regards to this, Linda (GEI FG3[165]) said, "we don't usually talk to them [about] the RSA", while Ria (GEI FG3[166]) added, "the goals are not discussed. That is not a priority".

8.5.1.4. Goal setting for clients with stroke

Participants felt that goal setting for people who have had a stroke was no different to goal setting for people with other conditions, as pointed out by Chris (RSA FG1[38]): "more often than not most people follow the same concept, strategy". They agreed that the various features of stroke creates more variability in the goals set, and the time frames involved, in comparison with other conditions, as illustrated in the quotes in Table 8.5.

Table 8.5: Illustrative quotes to demonstrate goal setting for stroke

FG1 (RSA)
[62]**Chris:** …the thing that is probably very crucial is, when we actually get to work with the person and how long is it since they have had the stroke, … For people who … may be just within the first year of their stroke, … goal setting may well be completely realistic for people in terms of recovery and getting some degree of functionality back in that time. If it is somebody … who has had a stroke a year, a year and half or two years ago, then the goal setting, I think changes to adherence ... Try this; attend this; if you can do that, then its fine.
FG2 (RSA)
[40]**Jema:** In terms of working with participants who have had a stroke …, as Mandy was saying earlier that, there are different levels and different degrees. So …, [it is] about setting goals around individuals' needs.
[112]**Lee:** I think that could be quite difficult though if someone has had a stroke, it depends on the severity of it. You often find that when they have the paralysis down on one side of the body, their speech is affected and they can [be] really demotivated to do anything at all … And I think from a stroke point of view, people will suffer from depression after a stroke because they have had their mobility affected, their speech affected, and I think just to have that additional person to motivate them … to set goals, I think that would be valuable.
FG3 (GEI)
[94]**Linda:** I think stroke … a massive effect it has got on their lives both physical and mental, goal setting is probably a more smaller, small, small stages for them. A lot of people need to basically start again with their speech, or trying to walk properly, and the psychological effect it has on their lives. So basically when you set goals, you have got to be small, precise with them as well. [95]**Ria:** More specific [goals].

8.5.2. **Perceptions of goal setting**

Two-sub-themes contributed to this theme: how the participants perceived the meaning of the term 'goal setting', and how they perceived the usefulness of goal setting.

8.5.2.1. Meaning of the term 'goal setting'

The participants provided various definitions when asked about the meaning of goal setting, such as: "planning ahead" (Mandy RSA FG2[16]), "working towards something" (Kate RSA FG2[17]), "focus in direction" (Jema RSA FG2[18]), and "setting targets, achievable targets" (Ria GEI FG3[10]).

8.5.2.2. Perceived usefulness of goal setting

All participants viewed goal setting as a potentially useful and effective tool both for the client and for themselves. The professionals felt goal setting gave clients something "to aim for" (Dan RSA FG1[98], Tom and Ria GEI FG3), or "to look forward to" (Tom and Ria GEI FG3[183]). It was also seen to instil "confidence" (Helen[97] and Lee RSA FG2[98], Tom GEI FG3 with agreement from Linda and Ria[202]) and a "sense of achievement" (Dan RSA FG1[98]).

The professionals also identified that goal setting was "a very good guide" (Mandy RSA FG2[132]) that helped them and the client "to measure how they are doing" (Linda GEI FG3[191]). It was also viewed as a "tool in motivating clients to become more active" (Ria GEI FG3[12]).

8.5.3. **Roles of the participants in their respective services**

Throughout the focus group discussion, the participants referred to their roles within their respective services and therefore, this theme was created.

8.5.3.1. Role as Referral Scheme Advisor

The sub-theme was related only to RSAs and therefore only to FG1 and 2. During the discussions, participants referred to their roles as RSA when asked about day-to-day practices. They also mentioned that their service was based on the Transtheoretical Model of Change (TTM). The TTM is a 'stage-based' model that was proposed to understand the nature of behaviour change (Prochaska and Norcross 1994, Prochaska and DiClemente 1983). A brief overview of the model is presented in Appendix 17. Challenges to goal setting were identified in relation to the service, and suggestions for more effective goal setting were also made in reference to their service and their roles. Quotes presented in Table 8.6 provide some examples where the participants referred to the service and their role within the service.

Table 8.6: References made by the Referral Scheme Advisors in relation to the service and their roles within the service (Focus Group 1 and 2)

[25]**Chris (RSA FG1):** I think in relation to the client group we work with, goal setting is pretty ineffective. That will [be] due to the stage of behaviour change, when they are referred to us. We often work with people who are reluctant to change in terms of health behaviours. The whole principle of exercise referral is that people should be …. The whole thing is based on the Transtheoretical Model of health change. So people should be almost in a position where they are ready to change.
[52]**Chris (RSA FG1):** … I think one of the things about this service is that, this service is very vague and its objectives are to support and encourage these people to lead a more healthy active lifestyle. The problem you have is measuring that… It is such a massive umbrella we work under here …
[66]**Frank (RSA FG1):** … We have a consultation with our client. We set goals for six months. First follow-up standard point is one month. … We offer the client the contact points. We say to the client if you wish ... more contact [than] the standard [could be provided]. More often than not, … they say I am fine with that …

[37]**Jema (RSA FG2):** In the consultation, we speak about health and how much physical activity they should be doing and [in] the adult populations, we discuss the health benefits as well. So they already have a broad understanding of how much they should be doing if possible and when we do goal setting, they seem to have an idea …
[80]**Jema (RSA FG2):** In our consultations even for activities like swimming, I would encourage the participant to keep their own training diary or an activity record diary as to what they are doing for their own motivation as well … We look at baseline, six months, 12 months appointment we talk about relapse prevention as part of their goal setting as well. You know to support them, that if they go back to the old [level], you say it is ok and build up their confidence to start it again.

8.5.3.2. Role as Group Exercise Instructor

This sub-theme was related only to GEIs and hence only to FG3. During the discussion the participants explained how the group exercise classes are conducted. Whenever questions were asked about day-to-day practices, references were made to the service and their role. Similar references were made when discussing the various challenges they faced regarding goal setting and when they put forth suggestions for more effective goal setting. Some instances where participants referred to their service and their roles within the service are presented in Table 8.7.

Table 8.7: References made by the Group Exercise Instructors in relation to the service and their roles within the service (Focus Group 3)

[15]**Linda:** One of the concerns we raised when different styles of rehabilitation team come into the class, how do we adapt to each one? … When you go into the standard group setting, you do not have the ability to set goals, sit down one to one. … So when they come in, we as teachers, deal with everyone at once …
[25]**Ria:** Realistically in the … [Group Exercise Scheme], with the amount of people … we can have, say the leisure centre can take up to 50 people in a [class] for Level Three, higher levels three and four. And there will be only two instructors. Then you are not going to get the time, realistically to goal set. Well, we do not get paid enough to do that.
[34]**Linda:** I think this is where training comes in place rather than general instructors. To be … [GEI] specifically you are taking a step back, so … you can understand. Instead of going right ok, so do this … and this… You are very much aware that you have got a variety of people in your class as well. … [36]**Linda**: … We were doing cardiac, stroke, brain injury, MS, you name it… every[one] was coming into the classes and … you are having to switch very quickly , very, very quickly, on how people work …
[41]**Ria:** Level One to Four and they increase in intensity. Level One being chair based. Some of the clients can stand, some can't, and that would be where most of the stroke clients get referred to Level One or Two. … [49]**Ria:** Then you have the strength and balance circuit. That is a step up. So perhaps even in the set up there is goal setting in the levels. People want to move on to the Level Two. So when the instructor in Level One feels ok that person is finding this easy. … he can progress them on to the next level.

8.5.4. **Goal setting approaches**

This theme was created to identify and explain the approach adopted by the participants in carrying out goal setting. Goal setting was undertaken as part of the Exercise Referral Scheme consultation and all the RSA in both focus groups agreed that goal setting was explicitly followed for all clients on an individual basis. On the other hand, GEI discussed that goal setting is not undertaken explicitly with their clients. To highlight this difference in the approaches, the approach followed by RSA was interpreted as a 'formal', but 'flexible' approach, while the approach followed by the GEI was interpreted as an 'informal' approach. These sub-themes are discussed in detail next.

8.5.4.1. Formal approach to goal setting

As noted above, this sub-theme relates only to RSA (FG1 and 2). Although the RSA participants in both focus groups agreed that goal setting was undertaken explicitly for all clients, variations within this approach were highlighted. All participants expressed that the goal setting process should be "client-led", however, in actual practice, they felt they were forced to adopt an "instructor-led" approach. Several reasons were put forward to explain this discrepancy in the goal setting approach, which are discussed under the theme 'challenges to goal setting'. This change in approach appeared to modify their roles within goal setting, from listening and guiding clients, to a role of prompting clients to set goals. Illustrative quotes that demonstrate this change are presented in Table 8.8.

Table 8.8: Illustrative quotes to demonstrate client-led versus instructor-led goal setting approaches adopted by Referral Scheme Advisors

FG1 (RSA)
[25]**Chris:** … Every now and then, we do get somebody with whom we can sit down and set very specific realistic goals and they do get them … Ultimately that is what we want, but … for the majority, it is more instructor-led. In many occasions … I feel I am actually prompting people in getting the goals for them. Teasing it out of them, I suppose. [26]**Frank:** Yes Chris is right. Sometime we have to almost tease it out of them, almost deliberately prompt them, but almost set it for them, so they choose that. But we try to be very careful. It is client-led, you make sure it is client-led set goals but because of the client group we work with it can be very hard …
[64]**Amy:** It [goal setting] is challenging. As we are saying, we are trying to make it client-led, but …
[16]**Chris:** …So it can be quite common in the way that we are indebted to set some realistic goals for them. It tends to be more instructor-led ….
FG2 (RSA)
[36]**Mandy:** It is just that you have to listen to the client. It has to be client-centred and it is what the client wants. … It is very much what they want … So we need to be specific to what their needs are. Then we try to draw information from them. Some people find that they want you to tell them what they should be doing; but you are trying to throw it back to them to decide this what I should be doing as opposed to you telling them.
[39]**Neal:** Often if it does not come from them, then it is not really a goal, if it comes from us, then I think it is not relevant. Because we have what motivates us as individuals, but may be it is not what they want …
[45]**Kate:** You have to make sure that you are taking a back seat and not, as Neal was saying, leading the direction. You want it to come from them because it is shown to have more adherence to it in that way than someone telling them what to do.

[91]**Helen:** The client mainly. With our guidance, obviously. We would not let them set an unachievable goal … You would break it down and explain why other things might be better. But ultimately it is their goals.
[95]**Mandy:** … They will need to break it down for us as to where they want to start and we are obviously there to guide them, like: maybe that is not a good idea, what about this. But then putting it back to them to say what they would like. Give them the choices and get them to decide.
[157]**Neal:** I think with relation to goals, it has got to come from the client themselves. It cannot be extrinsic. The ideal should be whatever motivates them and that is what you have to work on. Try and avoid the temptation to shape their responses, especially if you have got somebody who is particularly not very responsive, you are almost trying to put words in their mouth and that is very difficult For goals to have any sort of legitimacy, then it has to come from them…

8.5.4.2. Flexibility in goal setting

Although goal setting was explicitly done for all clients by the RSAs, flexibility within the goal setting procedure was strongly emphasised in both focus groups with RSAs (FG1 and FG2). They explained that goal setting procedure varies from client to client in terms of time frames, and types of goals. Illustrative quotes for this sub-theme are outlined in Table 8.9.

Table 8.9: Illustrative quotes for the sub-theme 'flexibility in goal setting'

FG1 (RSA)
[28]**Frank:** Certainly goal setting in our client group, it is flexible or changeable …
[34]**Beth:** It is flexible. It depends on the client and how confident they are in getting started. So you can shorten their next visit to set goal setting to say, over first month, and see. As Frank was saying, maybe joining the classes; setting something realistic for them and then maybe at that point setting some longer in terms of goals; just being flexible for the time being.
[47]**Frank:** In the end, it depends on each client … It changes from client to client.
FG2 (RSA)
[30]**Neal:** We are quite flexible into terms of what time periods we can break that into. We could set goals for the next two or three weeks, we could set goals for the next six months, and it depends on the activity you pick up for the individual, not what their actual long term goal is. Some folks will identify they need more support and you would make them into goals much shorter. People will see perhaps if they are more confident, then we set longer term goals. Then we will follow up on those as well in the following appointments.
[36]**Mandy:** … we might set goals for six months. But that's not clicking always with all the clients; it is very much what they want. They may say six months down the line is too far ahead. So we need to be specific to what their needs are.
[53]**Mandy:** … you go back to your goal setting and goals, you cannot always stick to it, you may have to change it from time to time.
[159]**Mandy:** I think goal setting is very positive but I think there needs to be room for change there. You cannot always to stick to that … There should be ways to work around it. You have to be able to adapt it and change.

8.5.4.3. Informal approach to goal setting

This sub-theme was only relevant to the GEIs (FG3). They stated that goal setting is not done explicitly with their clients but it is "part of the package" (Ria GEI FG3). As with the RSAs, the GEIs emphasised the importance of listening to their clients and gathering information from them in order to decide their exercise programme, however, these were done informally, as demonstrated in the quotes presented in Table 8.10.

Table 8.10: **Illustrative quotes for the sub-theme 'informal approach to goal setting' (only the Group Exercise Instructors – Focus Group 3)**

[15]**Linda:** … The easiest way in a group setting is to talk to people in conversations as they are going around in circuits to gauge what their life is like before and what they are capable of now, and what we can try to do to increase their strength and in particular, areas to get them back to some sort of normality as well.
[31]**Tom:** I think sub-consciously we are goal setting but we do not realise it. [32]**Ria:** We automatically do it. [33]**Tom:** When we are speaking to them, we are actually setting goals for them. But we are not going out of our way to be specifically setting goals. We do not realise it. When we talk to them, we find out what they can and can't do … so we give them an option.
[87]**Linda:** Sometimes when you sit down with a person and do one to one, it is very difficult to get that out of them. They [may] say 'I don't know'. But if you were talking to them in a general sense, [then] they will throw the information and you can pick it up quickly. That is where the teacher's role in the … [Group Exercise Scheme] works very well. They listen to what the clients say and they quickly work out. [88]**Tom:** It is informal; in one to one it is very formal.
[322]**Linda:** Although it [goal setting] is all verbal and all chit chat as well, I am actually being more attentive to the people that are coming to the class.

8.5.5. **Challenges to goal setting**

All three groups stated that they encountered several challenges that interfered with effective goal setting. To obtain a clear picture, the challenges are explained in three sub-sections based on whom these challenges relate to (i.e. the client, the professionals themselves, or the organisation).

8.5.5.1. Client-related challenges

The participants felt that goal setting became challenging when their clients provided little input into goal setting. They expressed that the client's stage on the Stage of Change Model determined the outcome of goal setting and cited that the majority of their clients were "not in the right stage of change". The client's background, such as level of education, financial status, and area of residence, and the client's personal circumstances, such as time, were seen as influencing factors regarding their involvement in goal setting. The participants also identified that the client's lack of understanding of the concept of goal setting influenced the level of participation in the goal setting process. This lack of understanding could have led to the clients viewing the professionals as experts, which was identified as one of the challenges by the participants. Due to all these difficulties, goal setting for some clients was seen as "a step too far". Verbatim quotes from each focus group to illustrate this theme are outlined in Table 8.11. In comparison, RSAs put forth more client related challenges than the GEIs.

Table 8.11: Illustrative quotes for the sub-theme 'client-related challenges'

FG1 (RSA)
[16]**Chris:** Quite often some of the clients we are indebted to set goals with, are possibly not a 100% ready and committed to health behaviour changes in their life.
[93]**Frank:** Goal setting is very effective, but it depends on where you are on the circle of change. [94]**Gary:** But as Chris says, they are not always in that stage. When they are ready you can do goal setting …
[25]**Chris:** … we often work with people who are reluctant to change in terms of health behaviours. … [27]**Gary:** Yes. I think the problem with that is, the clients that we most often see do not have any expectations. So they may be coming in with not a great deal of thought about exercise classes, coming into the gym, swimming.
[28]**Frank:** … they may go on to other classes we recommend, but the time may not suit them, or they may go along but do not enjoy it, because the client group is too old or something like that, or they do not like the gym because it costs too much money, and so we are tied by these sorts of constraints as well within goal setting.
[47]**Frank:** In the end, it depends on each client. You may have some clients coming from a very well-educated background, are ready to engage, ready to make life changes, and education to take on. They may come from a deprived area of …, where the lifestyle having a stroke at an early age with not quite as good education, not quite finances to back-up, these sort of things. [48]**Gary:** Yes, as Frank says, education levels can [influence]. So may be not gone through a goal setting exercise before or so. So the concept is quite new to the people as well … The concept is quite new to lot of people as well.

[57]**Dan:** It is quite hard to not input too much yourself, because you often do not get much back from the client … [58]**Frank:** The client gets to see us as the experts with all the answers … [59]**Dan:** Often it is what [do] you think, you tell me what to do, I will do it. [60]**Beth:** I have had that. You are the expert. You tell me what to do.
[64]**Amy:** It [goal setting] is challenging. …, due to the course of where I work, say pretty deprived area, and because they are quite new, they do not understand …, that is the challenge we are faced with working in a deprived area, education is not well.
[92]**Chris:** … Our health consultations in many cases are step too far for them. [93]**Frank:** To add on what Chris says. If the client is unmotivated and you cannot get on, you will try and motivate them and support them, but if you push, push too hard, a barrier just comes up and you can't get through them at all.
[144]**Chris:** In our environment, we are almost 80 or 90% of the time working with people who are lacking motivation … But I hate it sometimes. Sometimes it can be a waste of time. It is a step too far for some people. [145]**Frank:** They come in with a host of problems and maybe healthy active lifestyle maybe at the bottom of their list of mental health, finances. Where do we stick that into their lifestyle?
FG2 (RSA)
[39]**Neal:** That is more with the challenges, a lot of folk we get can be quite apprehensive and not a lot of knowledge … It is moving the conversation in the right direction, but that can also be difficult if the client is not forthcoming with us… Sometimes, they do not understand at all. You ask people on what they want to achieve and they will be 'I don't know', but they could possibly not be in the right stage of change, maybe they got in at the wrong time, that is a bit more difficult.
[45]**Kate:** …The barriers can primarily [be] from the client when they are not very forthcoming.

[104]**Jema:** … you find that the participants take the goal sheet and they do never look at it because you would not be asking them for it again… Sometimes you often see them put it in the bag at the end of the consultations and may … never refer it back … It is quite common that a lot of good things we do which is good practice; I don't think the participant sees the benefits of doing it, as much as you would like them to.
[107]**Kate:** We sometimes do get clients through the door that will say all the right things, go through all the goal setting quite easily, but then you just know that they are not going to stick to it or they are not ready for it or they are just quite good at knowing all the knowledge but actually putting it into practice is the problem.
[157]**Neal:** …. Try and avoid the temptation to shape their responses, especially if you have got somebody who is particularly not very responsive, you are almost trying to put words in their mouth and that is very difficult … People come in and say what they think they should be saying but it is not the reason why they are there.
FG3 (GEI)
[89]**Linda:** … they will need to be very willing… [90]**Ria:** Sometimes some are and some are not. It depends… [91]**Tom:** It depends on characters, yes [92]**Ria:** Yes. Everybody is different. It depends on their background, some like to be given a wee form and see it written. They will put it on a fridge and that is what my goal is. Some don't like that … So it is subjective, isn't it? Some people don't [like it]. They are not interested in it.

8.5.5.2. Professional-related challenges

Although both RSAs and GEIs identified challenges that were related to themselves, the challenges identified were different. The RSA participants identified that taking a step back was a huge challenge in goal setting. They recognised that in some cases they lacked confidence in setting realistic goals, especially with people who have had a stroke. This was attributed to lack of knowledge regarding stroke recovery. The participants also felt that there was a lack of measurement tools to gauge goal

achievement and this hindered the follow-up and review of goals. The GEIs, on the other hand, identified other barriers, such as their limitation in what they can do as instructors and their conflicting priorities. Illustrative quotes are provided as evidence for this sub-theme in Table 8.12.

Table 8.12: Illustrative quotes for the sub-theme 'professional-related challenges'

FG1 (RSA)
[16]**Chris:** …with people with stroke, … the goals that we do eventually set are quite often unrealistic from their perspective … So while we can set goals, the output from them or as to even if the goals are met or not is an area that I don't feel a 100% confident in, when I am setting goals.
[54]**Moderator:** What do you think, anything challenging about goal setting? [55]**Chris:** Taking a step back I think, isn't it? [56]**Dan:** In general, it is quite hard to not input too much yourself, because you often do not get much back from the client. [57]**Frank:** The client gets to see us as the experts with all the answers [59]**Beth:** I have had that. You are the expert. You tell me what to do.
[131]**Chris:** For people who have had a stroke, we can set goals with the clients … but even in the back of our minds we have no idea as to where this client is going. We do not know this is the outcome; this could be success for you. The nature of stroke dictates the outcome and we have got no idea on what that may be. So we are setting goals in relation to something that we may probably I don't think we will never get to … [132]**Frank:** When the client comes in and tells I am walking better, how do we measure that, apart from writing it in our notes? [133]**Dan:** They may have attended every gym and exercise classes that you have set for them, but if it has made any difference to their functionality, we don't know. [134]**Frank:** We go by them [135]**Chris:** They do not know where they can go and we do not know where they can go. So may be there is an education issue there.

FG2 (RSA)
[39]**Neal:** … You have to try and pull yourselves back from putting on to them what you think, and that you should be doing things. As Mandy was saying, it has to come from them as individuals. So it is difficult not to try take over the participant. It is moving the conversation in the right direction …
[45]**Kate:** … You have to make sure that you are taking a back seat and not, as Neal was saying leading the direction, you want it to come from them …
[80]**Jema:** … Make sure there is some sort of way rather than finding it a bit [difficult] on how we are going to measure it. Often we say to the participant that we do not do any fitness assessments, it is more of we do blood pressure measurement, height, weight, basic confidence levels. So basically we ask them to keep an activity diary.
[157]**Neal:** … Try and avoid the temptation to shape their responses, especially if you have got somebody who is particularly not very responsive, you are almost trying to put words in their mouth and that is very difficult …
FG3 (GEI)
[28]**Linda:** We do find as instructors we are very limited, very very limited as to what we can do and I think, it is probably the best thing for them is getting into a group.
[279]**Tom:** It [goal setting] is very low on the priority list of all we have to do. [280]**Linda:** For a group instructor it is personal [281]**Tom:** It is all about profit… it is all about getting as many people and keeping as many people in the class as we can. [282]**All:** Yes.

8.5.5.3. Organisation-related challenges

The participants felt that the schemes they were working within (the Exercise Referral Scheme and the Group Exercise Scheme) introduced certain restrictions, such as lack of time, lack of measurement tools, class structure and pay issues and that these, in turn, affected goal setting. Interestingly, the lack of time emphasised by the RSA participants

in focus group one was not seen as major barrier by those in focus group two. Some illustrative quotes that led to the creation of this sub-theme are presented as evidence in Table 8.13.

Table 8.13: Illustrative quotes for the sub-theme 'organisation-related challenges'

FG1 (RSA)
[52]**Chris:** The problem you have is … how do you determine how someone has improved their health and we are very restricted in sort of measurements that we are allowed to do. … It is such a massive umbrella we work under here and personally, I think, for us to determine the effectiveness or not, it may be better to incorporate some sort of measurements into our consultations.
[66]**Frank:** So ideally you … want to contact the client a lot more throughout that stage.
[94]**Gary:** But because of the time restrictions we have on the consultations, then we have got to try and get through with as much as we possibly can. But it is not an option with us at the moment to say, we'll have a wee discussion about what we are able to do within a gym setting or within behavioural change and then come back in about two weeks, a month's time; then we can set some goals. Unfortunately, time restrictions we all have, that is not feasible for us to do it at this time.
FG2 (RSA)
[50]**Helen:** We do get a quite a lot of time with our clients, it is an hour our first appointment, at the end of the hour or towards the end of that hour is really the time that most of us will probably do the goal setting after we have spoken for about half an hour at least. [51]**Moderator:** Do you think the time is enough to set goals with them? [52]**Helen:** Not all the time but majority of the time it is enough.
FG3 (GEI)
[15]**Linda:** When you go into the standard group setting, you do not have the ability to set goals, sit down one to one. We do not … get that personal time to do that.

[23]**Tom:** I think it is individual. I think you do not go in there with a set laid out plan that I am going to set goals for this individual. I think it is just the time factor. We do not have the time to do that.

[24]**Linda:** Yes we do not have [the time].

[25]**Ria:** Realistically in the … [Group Exercise Scheme], with the amount of people, as Linda said earlier which was not recorded, we can have, say the leisure centre can take up to 50 people in … [the class] for … higher Levels Three and Four. And there will be only two instructors. Then you are not going to get the time, realistically to goal set. Well, we do not get paid enough to do that.

[168]**Linda:** Purely because of the time factor. You … have got an hour's class and 30 people coming into that class at the same time. How are you going to go and stand there and go what is your goal today [and] what is your goal today? It is impossible. So therefore, we will only iterate that we will be talking to them as they are going around the circuit.

[178]**Moderator:** But you do not get to do a formal kind of things with your clients.

[179]**Ria:** Not in the … [Group Exercise Scheme]. No. We are not paid. We are paid only for the one hour session. That is what we are paid for.

[210]**Linda:** [challenge is] time, making it individual …

[211]**Tom:** The class is very structured**,** 15 minute warm up, 30 minute exercise and 15 minute cool down, that is it.

[214]**Linda:** And you have to try and get your answers [to goal setting] within that time.

[215]**Tom:** And you have got a class waiting to come in right as you finish.

…

[219]**Ria:** Then how do you remember [goal setting]? Then it is more documentation when already within in the … [Group Exercise Scheme] we have got to give statistics, we have got to get …

[220]**Tom:** Administration.

8.5.6. **Strategies and suggestions for more effective goal setting**

As goal setting is a part of the Exercise Referral Scheme consultations, the participants discussed some strategies that they were using at the time of the focus groups to overcome some of the above mentioned barriers.

For clients that were unsure of goal setting and goals, providing an opportunity for "the person to go away and have a think about it [goal setting] and then come back [for another consultation]" was seen as a successful strategy by Amy (RSA FG1[64]). Kate and Jema (RSA FG2[37]) felt that "discussing health benefits and physical activity benefits" prepares the client for greater involvement in goal setting. Helen (RSA FG2[50]) emphasised that "having knowledge of the client" and "building a big picture of the client first" results in more effective goal setting. Kate (RSA FG2[49]) pointed out that having "a knowledge base of the facilities they work in and knowing what they are talking about" helps in providing clients various options and thereby successful goal setting.

The participants in FG2 discussed a few strategies that they use to overcome communication difficulties with clients who have had a stroke. Mandy (RSA FG2[119]) stated that they can "use visual cues, and basically just draw pictures, anything that you could possibly do" to deal with communication difficulties. Kate (RSA FG2) provided an example from her practice, where the client's partner was involved to help with the client's communication difficulties, as seen in the excerpt below:

> [117]**Kate (RSA FG2):** I have a client who comes along to the gym sessions and she is only able to say yes and 'aye', that is the only two words she can say now after a stroke. So what happens is that her partner comes along and although there are two of us supervising the gym sessions, … her partner comes along as well. Giving more support, … as [she] cannot communicate in terms of, if she is feeling pain or if she is too tired, her husband because he is obviously with her all day, everyday, he is able to tell signs, from her eyes or maybe nodding. He is

able to know that a lot better than we do. So he comes along to the gym sessions with her.

Although Kate felt having a partner helped as in the above quote, Mandy (RSA FG2[119]) felt that having a partner may not always be successful, for the following reason: "in some case, partners do come in to deal with these things. But then doing goal setting is very hard, because he almost wants to do goals for her because she cannot communicate and then it is quite tricky …, because they cannot communicate fully with each other. It is frustrating for the patient." These differences again highlighted the flexibility within goal setting.

Although all participants acknowledged that they have had training in goal setting as part of their degrees or other courses, some felt an update would be useful, while others felt that they had sufficient knowledge. However, they all agreed that goal setting training specifically for clients with stroke would be helpful to update their knowledge (Table 8.14).

Table 8.14: Illustrative quotes to demonstrate thoughts on goal setting training

FG1 (RSA)
[116]**Moderator:** So do you think having formal training in goal setting would be helpful? Do you think it is required or maybe not? [117]**Chris:** No not really. [118]**Frank:** It would not do any harm. But it could cover old ground. [119]**Chris:** Frank is right. It would not do any harm at all. [120]**Frank:** It may freshen things up for us. [121]**Dan:** Yes … So there might be something out there that we do not know.
[130]**Frank:** Maybe we need more training in goal setting specifically for people with stroke, same as we need with goal setting with people who have had their hips replaced, as to what is their ultimate functionality they are going to get to. So we can be honest with them and say well, you are not quite going to get to there, but we hope to get you to this, what is really achievable to you.

FG2 (RSA)
[144]**Neal:** … training in [goal setting for] people coming from stroke, it would be useful, maybe to have a specialist to talk to you [about] what can actually happen. [145]**Neal:** But with general goal setting, I think we will be alright with that. I think we all have done it. [146]**Helen:** I cannot imagine, unless it has changed, or if somebody has come up with a new thesis on how to do it, I feel as I am OK.
[148]**Kate:** I think it is more a conjunction that you need. Terms of training in how to make sure you are doing it effectively, like motivational interviewing and sort of the combination aspects. It will be good training in that way, but just thinking specifically in terms of goal setting, as a separate thing, it should be more a combination of three or four things that you probably need training on in order to be more specific.
FG3 (GEI)
[286]**Moderator:** So do you think as exercise instructors you would benefit from some formal training in goal setting? [287]**Linda:** It is not going to make a difference I think. [288]**Ria, Tom:** But we could… [289]**Tom:** I think if it was like a specific goal setting that gives you ideas; it is good to get different ideas. [290]**Linda:** Yes it is good to get different ideas but it is all to do with the time.

For the other existing challenges, the participants put forth several suggestions to improve the current practice and thereby pave the way for more effective goal setting. Having an intermediate stage between referral and behaviour change consultation, selective use of goal setting with clients, and increased contact time were suggested by RSAs in FG1. Restructuring of classes with more instructors, smaller groups, or extra time were the suggestions provided by the GEIs in FG3. Evidence for these suggestions is provided as direct quotes in Table 8.15.

Table 8.15: Illustrative quotes to demonstrate suggestions for more effective goal setting

Need for an intermediate stage
[92]**Chris (RSA FG1):** … Our health consultations in many cases are step too far for them. I believe we should have an intermediate stage where people get informed of the benefits of exercise prior to them moving on to an official behaviour change health consultation. At the moment we have a direct referral to the behaviour change consultation …
[94]**Gary (RSA FG1):** … As Chris was saying ... our contact time … [to be] more beneficial, … [we] could have maybe a 20 minute or half an hour conversation about general health and behaviour change and then maybe two or three weeks down the line, bring in goal setting.
Selective use of goal setting
[92]**Chris (RSA FG1):** I think it should be an optional part of health consultation. For people who are focused and willing to make a health behaviour change, then yes, it should be incorporated. For people that are still demonstrating quite a high level of reluctance and sitting on the fence and not 100% convinced, then I think we should probably have the option of leaving it out now … Goal setting is a very effective strategy. It works very well with people who want it and who are in a right position to work it. For everyone else, I think in many ways it is ineffective and should be used selectively with people. … [94]**Gary (RSA FG1):** Going on from what Chris and Frank are saying what goal setting is for us, it is almost standardised … but it should be more as a tool as opposed to something that we have to go through with everybody.
More contact time
[66]**Frank (RSA FG1):** … I think goal setting would be, may achieve better results if it was standard for us to contact them at least every month for the first four or five months and that may achieve better goals.

Restructuring of classes
[28]**Linda (GEI FG3):** … If you are looking at future to try and sort this out. More money would have to go out to provide more instructors and more classes, so we can be more helpful to people. [29]**Ria (GEI FG3):** Yes smaller group.
[231]**Tom (GEI FG3):** I think it will show the person that we are actually giving them more time, it becomes more individual. It come[s] to having more time, or having more instructors per class, so that we can … instead of having one or two we can two or three, so two could run the class, while one could do the goal setting individually going around the group speaking to the individual. … [233]**Tom (GEI FG3):** We could do that in a smaller group setting.
[290]**Linda (GEI FG3):** … if they turn around and just say to us we are going to run the class for an hour and a half now and we are going to have a wee half an hour for a cup of tea and chat afterwards … As it stands just now there is no funding for that type of thing. It is in, and out. [291]**Tom (GEI FG3):** We need a restructuring of the class. [292]**Ria (GEI FG3):** Exactly. [293]**Linda(GEI FG3):** Yes.
[326]**Linda (GEI FG3):** Time, class numbers, goal setting would be perfect.

From all the excerpts used in this section, it could be seen that participants in FG2 (RSAs) were applying more strategies to overcome various barriers while participants in FG1 (RSAs) and FG3 (GEIs) were calling for changes within their respective services.

8.5.7. **Interactional elements of the focus group**

As explained in section 8.4.16, the positionality of the moderator, the roles and relationships described by the participants, the references made to

organisations/services, and use of language were explored in order to understand the emerging themes better. The overall group dynamics were also considered. These are discussed in the following sub-sections.

8.5.7.1. Positionality of the moderator

On exploring the positionality of the moderator, it emerged that the moderator performed all the roles that were assigned (i.e. focussing on the topic guide questions, asking probing questions, and asking for clarifications). Textual analysis showed that the questioning style of the moderator improved over the focus groups. For example, in the first focus group, the moderator asked the question about the meaning of the term goal setting and the familiarity of the participants with goal setting at the same time. Since this was a double-barrelled question, all the participants answered only the question on familiarity. However, this was corrected over the next focus groups, where the moderator asked single questions and waited for responses from all participants. The moderator stayed neutral to the discussion at all times. In focus group three, the moderator had to answer a direct question from a participant about the exercise service in Edinburgh. However, the moderator consciously gave a brief answer and did not provide any information that deviated or altered the discussion.

The reflective notes by the moderator were also considered at this stage. The moderator acknowledged being nervous at the start of the first focus group, with the nerves settling as the discussion began. At all points, the moderator felt that she was in control of the discussion without being intrusive. Since two focus groups were conducted on the same day with a short interval in between, the moderator reflected that extra effort was needed in the second focus group. This was to make sure that the probing questions or clarifications asked were related to the current set of participants, rather than the previous focus group participants. Textual analysis did not reveal any over interpretations in clarifications and probing.

8.5.7.2. Participant - roles and relationships

All participants discussed their roles as RSA or GEI clearly. The roles described were similar between focus groups one and two (both RSA). Overall, the participants appeared to consider client-centred care as a priority and discussed several things from the view that it would benefit the individual rather than themselves or the organisation. For example, Tom (GEI FG3[231]) stated that if more time was provided for goal setting, then "it will show the person that we are actually giving them more time, it becomes more individual". Similarly, Amy (RSA FG1[96]) discussed that she took the option of providing more time to the client to think about goal setting because "it would be beneficial to the person and me, rather than phone him up back after one month, or six months, … on how you are getting on, then they are not interested and not take[ing] that next step".

8.5.7.3. References to organisations or services

All the themes that were created appeared to be influenced by participants' roles as RSA or GEI within the Exercise Referral Scheme or Group Exercise Scheme respectively. These references to the organisation were considered crucial to understanding the views and experiences of the participants and hence were considered to be a distinct theme (section 8.5.3). Some of the challenges in goal setting were also related to the service of which they were a part. Similarly, suggestions for effective goal setting involved their particular service.

8.5.7.4. Use of language

The language used throughout the three focus groups was monitored. When analysing the language of each individual, no text or tone required particular attention, excluding one text unit. Most participants in FG1 expressed their views regarding goal setting being a compulsory part of their consultation. However, Chris appeared to be more

frustrated than the rest regarding this and it was highlighted in this strong use of language:

> [144]**Chris (RSA FG1):** But I hate it [goal setting] sometimes. Sometimes it can be a waste of time. It is a step too far for some people.

When the overall use of language was considered, differences between the RSAs and the GEIs were evident. Throughout the focus group discussion, RSAs (FG1 and 2) referred to 'Stages of Change' and considered goal setting as part of a behaviour change intervention. On the other hand, goal setting was generally seen by the GEIs as "setting targets" (Ria GEI FG3[10]) and "stepping up between levels" (Tom GEI FG3[16]). Again, this appeared to be related to their specific roles as RSAs or GEIs.

8.5.7.5. Group dynamics

Good interaction was seen between all participants in all three groups, with most of them contributing to the discussion at all points. Only one person in FG1 appeared to be very quiet and did not interact as much as the others. However, involvement was noted in the form of nodding in agreement of others' views and responding when the moderator asked for group consensus when summarising key points throughout the focus group. This person had not been involved in a focus group before, which could be considered a reason for limited participation. Another reason could be that one participant in this focus group was more dominant than the others and this could have suppressed the other person. However, the moderator ensured that all participants were given opportunities to express their opinions and that the focus group continued smoothly.

Good group dynamics were evident when participants felt free to provide examples from their work to emphasise or validate points made. Others' opinions were valued and in certain cases, opinions were changed as a result of the discussion. Most times, the participants acknowledged the comments made by the previous speaker and moved the discussion further. All the participants within each focus group knew each other and

were very comfortable with each other, demonstrated in the way that they completed each other's sentences more than once. They also asked questions amongst themselves for clarification. Illustrative quotes for each of the above points are presented in Table 8.16.

Table 8.16: Illustrative quotes to demonstrate group dynamics

Change of opinions
FG1 (RSA) [109]**Moderator:** So do you think, having formal training in goal setting would be helpful? Do you think it is required or may be not? [110]**Chris:** No not really. [111]**Frank:** It would not do any harm. But it could cover old ground. [112]**Chris:** Frank is right. It would not do any harm at all. [113]**Frank:** It may freshen things up for us. [114]**Dan:** Yes. There might be a different, as we say we follow SMART goals. But there might be a better method to do goal setting or better way to record it. SMART goals can be sometimes very hard to be specific with clients. So there might be something out there that we do not know. … [130]**Frank:** Maybe we need more training in goal setting specifically for people with stroke. [131]**Chris:** That is right. For people who have had a stroke, we can set goals with the clients if that is what they want but even in the back of their minds we have no idea as to where this client is going …
FG3 (GEI) [286]**Moderator:** So do you think as Exercise Instructors, you would benefit from some formal training in goal setting? Do you think that is going to add anything? [287]**Linda:** It is not going to make a difference I think … We use our common sense, we can. [288]**Ria, Tom:** But we could.

[289]**Tom:** I think if it was like a specific goal setting that gives you ideas; it is good to get different ideas.

[290]**Linda:** Yes it is good to get different ideas …

Acknowledging previous speakers

FG1 (RSA)

[92]**Chris:** Personally I think goal setting should be an optional part of the health consultation with the clients we work with …

[93]**Frank:** To add on what Chris says. If the client is unmotivated and you cannot get on, you will try and motivate them and support them, but if you push, push too hard, a barrier just comes up and you can't get through them at all.

[94]**Gary:** Going on from what Chris and Frank are saying what goal setting is for us, it is almost standardised in that what it means to do in the consultation but it should be more as a tool as opposed to something that we have to go through with everybody. But as Chris says, they are not always in that stage … As Chris was saying ... our contact time … [to be] more beneficial, … [we] could have maybe a 20 minute or half an hour conversation about general health and behaviour change and then maybe two or three weeks down the line, bring in goal setting.

FG2 (RSA)

[39]**Neal:** … as Mandy was saying, it has to come from them as individuals …

[40]**Jema:** In terms of working with participants who have had a stroke as well, as Mandy was saying earlier that there are different levels and different degrees, so as well, about setting goals around individual's needs…

Completing each other's sentences

FG3 (GEI)

[198]**Tom:** I think you can reach one goal, see that goal has reached and then set another goal to reach

[199]**Ria:** As lets move on

[200]**Tom:** So you are always moving forwards. I think people always like to go forwards…

[201]**Ria:** As human beings.

[202]**Tom:** I think it is confidence booster.

[203]**Ria and Linda:** Yes, confidence booster.

Asking questions amongst themselves

FG3 (GEI)

[15]**Linda:** For example, if someone had done bowling before, now is struggling with walking, bending you then say, ok, why don't you kind of try and work on this one and so the easiest way in a group setting is to talk to people in conversations as they are going around in circuits to gauge what their life is like before and what they are capable of now and what we can try to do to increase their strength and in particular areas to get them back to some sort of normality as well. Tom, do you get the same thing?

[16]**Tom:** We have got them, in particular, in the … [group exercise] classes …

8.5.8. **Theory development**

To move towards theory development, the relationships within the data were first explored. This revealed that several sub-themes that were part of different themes appeared to be linked with each other. These linkages that were apparent in the text were then interpreted to provide an overall relationship between the main themes, and explain the participants' views and experiences on goal setting. Further, each focus group appeared to have one key message and this was also highlighted.

8.5.8.1. Relationships between themes

The role of the participants as RSA and GEI (theme 2), along with the various challenges they faced (theme 4), appeared to influence the approach the participants adopted for goal setting with their clients (theme 3). This approach to goal setting in everyday practice (theme 3), when compared with their perceptions of the effectiveness of goal setting (theme 1), highlighted the differences between actual practice (theme 3)

and theory (theme 1). These underlying factors appeared to lead the participants to discuss several strategies and put forth suggestions (theme 5) that would bridge the gap between theory and actual practice, thereby more effective goal setting. Figure 8.3 provides an illustration of the suggested relationships between the themes.

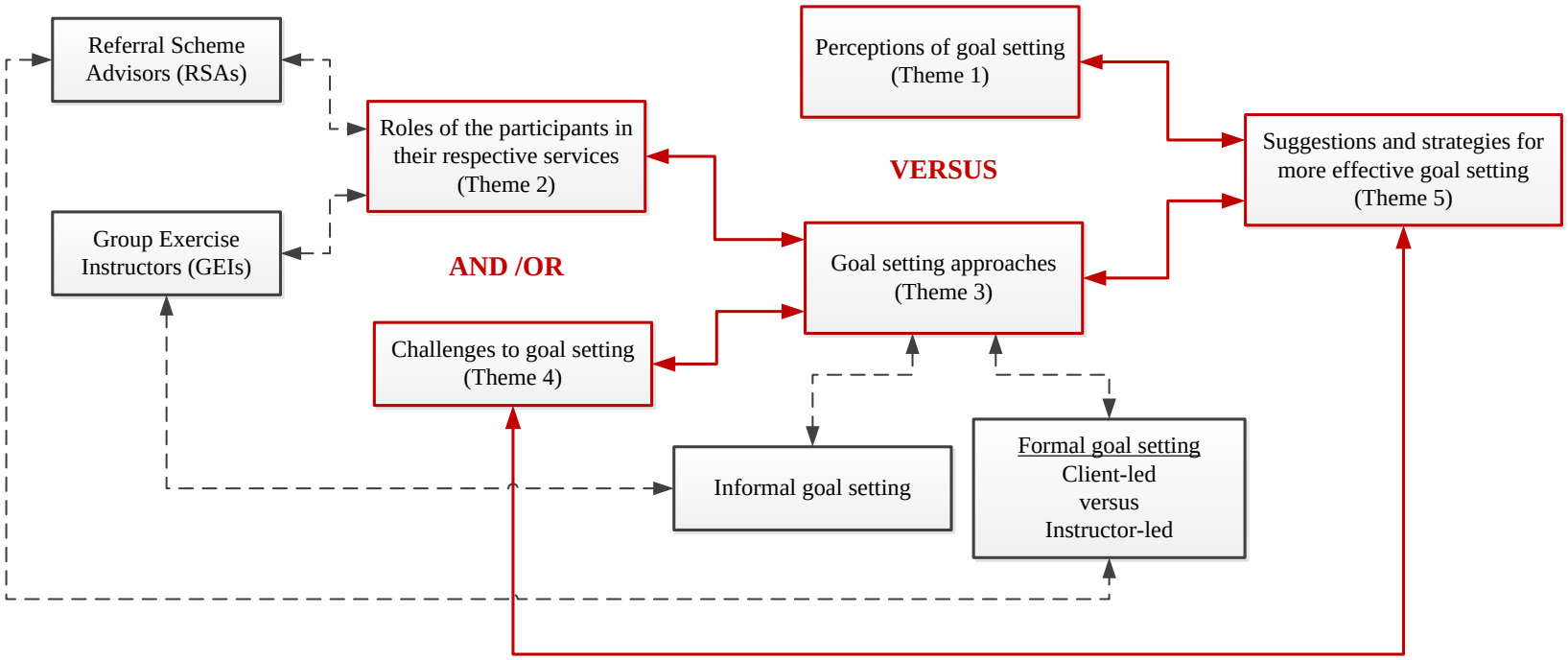

Figure 8.3: Illustration of the suggested relationships between the themes

Five quotes were selected to demonstrate the relationships between the different themes as illustrated in Figure 8.3 and these are presented next. These quotes were selected because the links were either clearly apparent in the quote, and/or several themes were linked within the same quote. To understand the context better, the quotes are presented in full with the links highlighted in bold and italics.

The first selected quote was the discussion by RSAs Chris and Frank in FG1, as seen below:

> [25]**Chris (RSA FG1):** I think in relation to the client group we work with, goal setting is pretty ineffective. That will be ***due to the stage of behaviour change, when they are referred to us***. We often ***work with people who are reluctant to change in terms of health behaviours*** … The whole thing [service] is ***based on the Transtheoretical Model of health change.*** So people should be almost in a position where they are ready to change. If people are in that position, then ***goal setting definitely can be realistic positive thing*** … Every now and then, we do get somebody with whom we can sit down and set very specific realistic goals and they do get them, that ***ultimately that is what we want but*** … for the majority ***it is more instructor-led***. In many occasions … I feel I am ***actually prompting people in getting the goals for them, teasing it out of them***, I suppose.
>
> [26]**Frank (RSA FG1):** Yes sometime Chris is right. Sometime[s] we have to ***almost tease it out of them, almost deliberately prompt them but almost set it for the,*** so they choose that. But ***we try to be very careful***. It is client-led, ***you make sure it is client-led set goals but*** because of the ***client group we work with it can be very hard.*** These ***clients do not see what goals they want to set***, you do find yourselves saying I would suggest that you may use this class and this may benefit you.

In this excerpt, Chris (RSA FG1) identified how client-related challenges modified their formal approach to goal setting, from client-led to instructor-led. How the change in

approach created professional-related challenges, such as taking a step back, was also raised within this quote. Their role as RSAs within the service was mentioned along with Chris's perceptions of the effectiveness of goal setting. By doing this, the difference between perceptions and actual practice was highlighted. These points were immediately supported by Frank (RSA FG1), which strengthened the links made. Based on the links apparent between the sub-themes in the above quote, the following themes were interpreted to be linked:

(i) Goal setting approaches (theme 3) and challenges to goal setting (theme 4),
(ii) Goal setting approaches (theme 3) and perceptions of goal setting (theme 1),
(iii) Goal setting approaches (theme 3) and roles of the participants within their respective services (theme 2).

The second quote from Neal (RSA FG2) was selected to demonstrate linkages between sub-themes and thereby themes.

> [39]**Neal (RSA FG2):** Often ***if it does not come from them, then it is not really a goal.*** If it comes from us, then I think it is not relevant because we have what motivates us as individuals, but may be it is not what they want. That is more with the challenges, a ***lot of folk we get can be quite apprehensive and not a lot of knowledge***. You have ***to try and pull yourselves back*** from putting on to them what you think, and that you should be doing things. As Mandy was saying, it ***has to come from them as individuals***. So it is ***difficult not to try take over*** the participant. It is ***moving the conversation in the right direction***, but that can also be ***difficult if the client is not forthcoming*** with us or anything sometimes. They ***do not understand at all***. You ask people on what they want to achieve and they will be 'I don't know', but they could possibly ***not be in the right stage of change, may be they got in at the wrong time,*** that is a bit more difficult.

Similar to the quote by Chris (RSA FG1[25]) presented earlier (p.353), Neal also identified how client-related challenges influenced their formal approach to goal setting. He also discussed how these challenges introduced professional-related challenges, and

indirectly modified their role within the service. Based on these links the following themes were interpreted to be linked:

(i) Goal setting approaches (theme 3) and challenges to goal setting (theme 4),

(ii) Goal setting approaches (theme 3) and roles of the participants within their respective services (theme 2).

The third selected quote was by Linda (GEI FG3).

> [15]**Linda (GEI FG3):** It is ***very difficult in a group to actually individually set goals*** and unfortunate thing is, if you have got ***20 to 35 people in your class*** and you have got a ***mixture between cardiac and stroke*** … When you go into the ***standard group setting, you do not have the ability to set goals***, sit down one to one. We do not have the, ***we do not get that personal time to do that*** and usually they come … via the … [Exercise Referral Scheme]. They … set goals. So when they come in, ***we as teachers, deal with everyone at once*** … and so the easiest way in a group setting is ***to talk to people in conversations as they are going around in circuits*** to gauge what their life is like before and what they are capable of now and what we can try to do to increase their strength and in particular areas to get them back to some sort of normality as well.

While the selected first two quotes demonstrated mainly the influence of client-related challenges to the approaches of goal setting, Linda (GEI FG3[15]), in her focus group, discussed how the organisational-related challenges and professional-related challenges influenced their approach to goal setting. In this quote, Linda also explained how their role as GEIs influences the informal approach they adopt for goal setting with their clients. The linkages between these sub-themes led to the interpretation that the following themes could be linked:

(i) Goal setting approaches (theme 3) and challenges to goal setting (theme 4),

(ii) Goal setting approaches (theme 3) and roles of the participants within their respective services (theme 2).

The fourth quote selected was by Chris (RSA FG1):

> [92]**Chris (RSA FG1):** Personally I think ***goal setting should be an optional part of the health consultation with the clients we work with***. Our health consultations in many cases are ***step too far for them***. I believe ***we should have an intermediate stage*** where people get informed of the benefits of exercise prior to them moving on to an official behaviour change health consultation. At the moment we have a direct referral to the behaviour change consultation. Now ***depending on the person's motivation and willingness to change at the baseline will determine the successfulness of the goals and the outcome***. I think it should be an optional part of health consultation. For people who are focussed and willing to make a health behaviour change, then yes, it should be incorporated. For people that are still demonstrating … sitting on the fence and ***not 100% convinced, then I think we should probably have the option of leaving it out now***. Goal setting is a ***very effective strategy***. It works very well with people who want it and who are in a right position to work it. For everyone else I think in many ways it is ineffective and ***should be used selectively with people.***

In this quote, Chris articulated why the service needed modifications regarding goal setting by making references to the challenges the clients posed and their current practice. Within his explanation, he also identified the benefits of goal setting and his perceptions of who may or may not benefit from goal setting and how his suggestion could make goal setting more effective. Based on these links, the following themes were interpreted to be related to one and another:

(i) Perceptions of goal setting (theme 1) and strategies and suggestions for more effective goal setting (theme 5),

(ii) Challenges to goal setting (theme 4) and strategies and suggestions for more effective goal setting (theme 5),

(iii) Goal setting approaches (theme 3) and strategies and suggestions for more effective goal setting (theme 5).

The quote by Linda (GEI) from FG3 was selected as the fifth quote:

> [28]**Linda (GEI FG3):** We do find ***as instructors we are very limited***, very, very limited, as to what we can do … If we can get them in and at least get them working in that time, which is not ideal, but it works with us because we have to do it. Over time we get to know them, we know their strengths and weaknesses. They also become more honest with us as well. I think smaller groups would do more ideal … ***If you are looking at [the] future to try and sort this out, more money would have to go out to provide more instructors and more classes*** so we can be more helpful to people.

In the above quote, Linda put forth a suggestion to improve goal setting within their service by relating it to the professional and organisational related challenges faced. References were also made to the informal approach they adopted due to the challenges they faced. As these sub-themes were linked, the following themes were interpreted to be linked:

(i) Challenges to goal setting (theme 4) and strategies and suggestions for more effective goal setting (theme 5),

(ii) Goal setting approaches (theme 3) and challenges to goal setting (theme 4).

8.5.8.2. Key messages from each focus group

Although it was possible to create several common themes from the three focus groups, each focus group appeared to have one key message that was emphasised within the focus group discussion (Table 8.17). All three focus groups perceived that goal setting could be effective in principle. However, participants of FG1 were more critical of the strategy, while participants of FG2 emphasised the flexibility required within the

process. Participants of FG3 put more emphasis on how goal setting processes could be improved within their service.

Table 8.17: Key messages from individual focus groups

Key message from FG1
"Goal setting is an effective strategy if applied to the right person at the right time. If not, it is a waste of time".
Key message from FG2
"Goal setting is very positive but there should be ways to work around it - you have to be able to adapt it and change."
Key message from FG3
"More time, small class numbers, money - Goal setting would be perfect."

8.6. **Discussion**

Two focus groups with RSAs and one focus group with the GEIs were conducted with the aim of exploring the perceptions and experiences of these exercise professionals in goal setting after stroke. The results are first summarised and then discussed in relation to the published literature. The strengths and limitations of the study will be identified next. The implications of this study are discussed with recommendations put forth for practice and further research.

8.6.1. **Summary of results**

The main themes identified included a description of the goal setting procedures; the perceptions of the professionals of the meaning and usefulness of goal setting; the roles of the participants in their respective services; the various approaches to goal setting adopted; the challenges or barriers faced that impacted on goal setting; and strategies and suggestions that could improve goal setting practice.

Overall, the participants felt that the benefits of goal setting that they perceived were not always translated into actual practice due to the various challenges encountered. They discussed strategies that they used to overcome some of the challenges; however, they strongly felt that changes need to be implemented to ensure more effective goal setting within their services.

8.6.2. **Comparison of results with published literature**

The researcher is not aware of any literature that explores the experiences of exercise professionals on goal setting; therefore, no direct comparisons could be made. Studies which analysed experiences of goal setting of other professionals, such as Allied Health Professionals and Doctors both within stroke rehabilitation and mixed settings had findings in line with those of the current study and are discussed in the sections that follow.

In more than one way, the findings of Kuipers et al. (2004) could be compared to the current study and hence are discussed here in more detail. The themes identified by Kuipers et al. (2004) from their interviews with six rehabilitation co-ordinators working in acquired brain injury rehabilitation were similar to those identified in the current study. Identical quotes to those in the current study were presented to express the views of professionals that goals need to be client-centred, suggesting similar experiences (Kuipers et al. 2004). In that study, the authors explained that both the clients and the professionals influenced the goal setting process. Cognitive, psychosocial, and practical issues relating to the client were seen as the client influences on goal setting, while professional skills, values, work experiences and organisational factors were put forth as professional influences on goal setting. These relationships could be easily merged with the relationships that were illustrated in Figure 8.3. This similarity in experiences, although in a varied setting with a different professional group, strengthens the validity of the findings of the current study.

8.6.3. **Discrepancies between theory and practice**

All participants were familiar with goal setting and its principles and had training in general goal setting. This was not a surprising finding given the emphasis that has been placed on goal setting in recent days in all fields (Siegert 2010). The concept of client-centeredness could also be viewed in a similar manner (Brown et al. 2013) and again, it was no surprise that the exercise professionals emphasised client-led goal setting. The participants also viewed goal setting as a potentially effective strategy. However, the finding that their knowledge of goal setting and their perceptions regarding the potential effectiveness of goal setting were not always translated into practice was a cause of concern, but not a new finding.

The exercise professionals in this study pointed out that client-led goal setting could not be carried out with the majority of the participants and was often transformed into instructor-led goal setting. This apparent struggle between client-led and instructor-led goal setting has been raised previously (Leach et al. 2010, Conneeley 2004). Only one professional followed true client-led goal setting, while the majority involved the clients only to a certain extent in the study of Leach et al. (2010), highlighting the discrepancy.

8.6.4. **Challenges to goal setting**

Various challenges to goal setting were identified by the participants to explain the modifications they made within their practice regarding goal setting. Most of the challenges discussed by the exercise professionals were also identified by the participants in the study of Kuipers et al. (2004). Interestingly, the various factors were considered as ‘influences’ in that study and not ‘challenges’ as in the current study. As literature on goal setting in stroke often discusses the challenges when discussing goal setting (Leach et al. 2010), the moderator coined a question using the term ‘challenges’ and this may have led to the participants using the term ‘challenges’.

On discussion of the challenges to goal setting in stroke, professionals in rehabilitation settings found communication and cognitive impairments of the patients to be a major client-related barrier (Leach et al. 2010, Hale 2010). The participants in the current study did identify the characteristics of stroke as difficulties, however, these were not emphasised as strongly as the readiness of the client to engage in goal setting. This could be attributed to the fact that the exercise professionals in the current study were working with a mixed population and not specifically with stroke as in the studies mentioned earlier (Leach et al. 2010, Hale 2010). The client's lack of engagement in goal setting may have been the most common challenge encountered in their mixed client group and therefore, that may have stood out when compared with the cognitive and communication difficulties of a client with stroke. It should be noted that this is speculation and the actual number of stroke clients and the ratio within their mixed client group was not known. Further, participants in one group discussed strategies such as visual cues, having a carer to help to cope with communication problems. Therefore, it could be assumed that the participants were more confident in dealing with these difficulties and hence, it was not seen as a major barrier to goal setting.

The same reason that the participants were working in a mixed population could explain why the exercise professionals felt that they lacked knowledge regarding stroke recovery and recognised a need for training in goal setting in this particular population to ensure realistic goals were being proposed and set. As the participants were working in a mixed client group, it may not be possible to be experts in all conditions, and hence the lack of specialist stroke knowledge. It should be also noted that the lack of knowledge regarding stroke recovery was not identified as professional-related barrier in any of the studies that were included in the systematic review (chapter 4). Again, all these studies were stroke-specific and hence professionals involved would have had more knowledge on stroke. Interestingly, in the systematic review, this was put forth by the HCP's as a client-related barrier (Leach et al. 2010, Wressle et al. 1999a, Jansa et al. 2004, Hale 2010, Laver et al. 2010).

Excluding the above, the other challenges identified in the current study, such as clients' lack of motivation (client-related challenges), and lack of time (professional-related challenge), were also pointed out by other professionals in various studies (Kuipers et al. 2004, Young et al. 2008, Van de Weyer et al. 2010).

8.6.5. **Roles of the participants in their respective services**

From the data analysis, it emerged that the participants' roles in their respective services and the service itself had a major influence on the views and experiences of the participants in relation to goal setting. Therefore, it was crucial to discuss this in more detail. However, it should be remembered that the aim of the study was to explore the experiences of goal setting and not to conduct a service evaluation.

8.6.5.1. Referral Scheme Advisors and the Exercise Referral Scheme

RSAs were involved in exercise consultation to facilitate behaviour change and discussed that their service is based on the Transtheoretical Model (TTM) (Prochaska and Norcross 1994, Prochaska and DiClemente 1983). Although this model was initially proposed in the field of smoking cessation (Prochaska and DiClemente 1983), this framework is now increasingly being used to understand physical activity behaviour change (Biddle and Mutrie 2008, Prochaska and Marcus 1994). Exercise consultations such as these by the Exercise Referral Scheme are usually based on this model of behaviour change and are being recommended to facilitate physical activity behaviour change in various populations (Kirk et al. 2007, Hughes et al. 2007, Henderson et al. 2010). These consultations combine motivational interviewing and cognitive behavioural approaches to promote physical activity (Kirk et al. 2007, Henderson et al. 2010). Goal setting forms an integral part of these exercise consultations (Biddle and Mutrie 2008, Kirk et al. 2007, Hughes et al. 2007) and the Exercise Referral Scheme involved in the current study appeared to be no different. The client being in the wrong stage of change for effective goal setting was the major client-related barrier identified

by the participants. However, it was not clear how the participants decided the client's level on the stages of change, i.e. whether the participants filled in a questionnaire that would help to identify the level they are at or were the levels decided by the RSAs themselves. If it was the latter, then the RSAs' preconceived notions of stages of change and the behaviours associated with them may influence the identification of the appropriate stage of change, thereby introducing bias into the service. Furthermore, RSAs often linked a client's level of engagement and readiness to be involved in goal setting to the client's level of education and background. Again, it is not clear how and based on what these links were made. Such linkages and targeting resources based on these have revived several criticisms (Littell and Girvin 2002).

This leads onto the RSAs' criticism of the service regarding the demand for standard use of goal setting with all clients and their suggestions of using goal setting selectively with people. It was proposed that for goal setting to be effective, it should be undertaken with people who are at the right stage of change, and who are willing and motivated to make a behaviour change. These people would be in the 'preparation' stage or higher on the TTM (Prochaska and Marcus 1994, Prochaska and Velicer 1997). Therefore, if RSAs are required to set goals with all participants, irrespective of the stage of change of the client, then this would mean a mismatch of stage-based strategy, and a criticism of the service as a whole. Most of the participants in this study identified this mismatch and this may be an indication of their understanding of why and how goal setting works. Therefore, their suggestion of using goal setting selectively with people could be justified in line with the TTM.

However, the question arising from the above discussion is: what can or should be done for the participants who are not in the right stage of change for goal setting? It could be said that services such as the Exercise Referral Scheme are designed to help people move through the different stages of change towards maintenance of physical activity and/or healthy lifestyle by the use of appropriate strategies, such as information

provision, education, discussion of barriers and motivators to name a few. Therefore, if clients are in the lower stages of change (i.e. precontemplation and contemplation), it would be the role of the RSAs to apply the appropriate cognitive and behavioural strategies to facilitate movement towards the higher stages of change (i.e. preparation and above), at which point goal setting could be applied more effectively.

This then leads onto the other suggestions put forth by the RSAs, such as having an intermediate stage where the clients are informed of the benefits of improved physical activity and having more face-to-face contact time with the client. Both these suggestions could be viewed as strategies that would help the clients move to higher stages of change. Since the service was based on the TTM model, the first suggestion should already be a part of the service ideally, in line with the TTM. However, if participants are raising it as a suggestion, then the application of theory into practice within this service could be questioned. Feasibility issues such as time and cost may be involved, but nevertheless, the importance of applying theory in the correct manner in practice is crucial to the success of these services. With regard to the suggestion of more contact time with the client, it was not clear if it related to goal setting in particular, or the service as a whole. If it was the former, then there appeared to be a mismatch between participants. While RSAs in FG1 felt that goal setting within their one hour of consultation was difficult, RSAs in FG2 felt that the time was sufficient in the majority of the cases. However, flexibility in the timings of the consultation could alleviate this problem of lack of time. Again, feasibility issues would have to be considered.

Lack of measurement tools to evaluate goal achievement was raised by some RSA participants. Although various tools such as the COPM are available, the applicability of these tools in this setting needs to be addressed first. Further, the professionals would need to be trained in the use of these outcome measures, to ensure correct usage.

One of the RSAs stated that the concept of goal setting was new to some of the clients and that this influenced their involvement in goal setting. Evidence from the systematic review (chapter 4), and other literature emphasises the importance of education of clients on goal setting to overcome challenges to goal setting (Leach et al. 2010, Chen et al. 2002, Young et al. 2008, Sugavanam et al. 2013, Laver et al. 2010, Baird et al. 2010, Cott 2004, Van de Weyer et al. 2010, Baker et al. 2001, Sumsion and Smyth 2000). Client education on goal setting was not mentioned in the focus group discussions, and could be put forth to this population to overcome the above challenge.

Other recommendations proposed in the systematic review (chapter 4) and other literature for professionals in rehabilitation such as, training professionals in goal setting methodology for people with stroke and educating them on potential barriers to goal setting and successful strategies to overcome these, could all be applicable to this population of exercise professionals, based on their responses in the focus groups (Chen et al. 2002, Sugavanam et al. 2013, Rosewilliam et al. 2011, Barnard et al. 2010, Sumsion and Smyth 2000, Elsworth et al. 1999).

8.6.5.2. Group Exercise Instructors and the Group Exercise Scheme

As with the RSAs, the experiences of the GEIs appeared to be influenced by their roles. The GEIs stated that since the classes are group classes, only an informal approach to goal setting could be adopted. They also added that if extra time were provided, a more formal approach could be adopted. Ironically, RSAs who were given the time to do formal goal setting with all clients as part of their behaviour change consultation felt that selective use of goal setting would be more beneficial. This again highlights the differences in perceptions between individuals. The GEIs also discussed the issues of pay and money when discussing goal setting. The self-employed status of the participants could have influenced this discussion. This also tied in with some of the participants' comments on the priority of the service to increase class numbers.

Another important factor to be considered is the passing on of goals between the services within the same organisation. The RSAs stated that they did not pass on the decided goals to the GEIs. If the clients were working towards a functional goal, it would appear logical for the GEIs to be aware of these goals so that they could adopt them in their classes and motivate the client to achieve their goals. Exercises within the Group Exercise Scheme could also be modified accordingly. However, this was not the case in actual practice. Hence, it appears that a potential continuity within the goal setting process is lost. Although the RSAs had follow-up appointments with the clients to review goals and the GEIs described identifying the goals of the clients through informal conversations, goal setting and progress may improve if the goals were shared – provided the client gave their consent to this information being passed on. Data confidentiality issues were raised in relation to this, however, these could be revisited to ensure the client's goal setting is followed through by all the professionals involved.

8.6.6. **Strengths of the study**

To our knowledge, views of exercise professionals regarding goal setting have not been explored previously and hence the novelty of the study is regarded as its major strength. By holding discussions with exercise professionals in two different services, opportunities were created to explore similarities and differences. In addition, the influences of the service on the professionals' experiences were also highlighted. Care was taken to ensure all rigour criteria were met, thereby improving the quality of the study.

8.6.7. **Study limitations**

The study had several limitations. If this study had been conducted with exercise professionals of the EaS service as planned, then this would have allowed for discussion of the goal setting intervention designed as part of this programme of work. However, this was not possible, and a new recruitment source had to be used in this study.

It is recommended that focus groups be conducted with six to ten participants. However, due to recruitment difficulties, only three participants could be involved in the focus group with GEIs. This small number could have limited the scope of the discussion. Further, two focus groups could not be conducted with this sub-group. Therefore, the experiences shared could not be compared with others within this sub-group, as done for the RSAs. Although data saturation through repeated focus groups was not possible within the scope of this study, analytical saturation was achieved by analysing the data until no new themes emerged.

It should also be noted that the participants were from one organisation and therefore, the transferability of the findings may be limited.

Conducting two focus groups on the same day without a prolonged break could be criticised. However, the moderator reflected on it and no limitations were apparent. The moderator was novice to this type of research and it is not known if an experienced person could have widened the scope of the discussion.

Finally, the participants were working with a mixed population and therefore, experiences shared were not strictly related to stroke. However, all participants had experience of working with the stroke population. For any experience shared, probing questions relating to stroke were asked and responses obtained. Further, they were encouraged to give examples with reference to stroke wherever possible. An advantage was also that having participants with varied experience allowed for comparison of experiences between different conditions.

8.6.8. **Study implications**

The study has brought to the forefront the experiences of goal setting of an under-researched population. Goal setting practices, the difficulties encountered and how it could be modified have been highlighted. The difficulties in translating theory into

practice have been also been identified and discussed. If goal setting were to be introduced in a new exercise after stroke service, these findings can be taken into consideration to ensure effective goal setting. Recruiting self-employed exercise instructors was found to be difficult for this study. Therefore, alternative methods of recruitment should be considered if required in the future.

8.6.9. **Recommendations for practice and research**

Suggestions put forth by the participants to improve goal setting practice should be explored to enable the gap between theory and actual practice to be bridged. It is recommended that professionals be provided with and trained in the use of several strategies (e.g. use of outcome measures, training in goal setting for stroke) to ensure that the target population receives optimum benefit from the service. This study also needs to be replicated with exercise professionals involved in other services in different locations to explore whether results are transferrable to different contexts. The experiences of service users should be explored to obtain an overall picture of goal setting in this setting. Further, the effects of goal setting in this setting should also be evaluated to identify the extent to which the expected benefits of goal setting are achieved.

8.7. **Conclusion**

The perceptions and experiences of exercise professionals regarding goal setting was explored through three focus groups in this study. The main interpretive themes that emerged included: perceptions of goal setting, roles of participants in their respective services, goal setting approaches, challenges to goal setting, and strategies and suggestions for more effective goal setting. The results suggested that exercise professionals perceived goal setting to be an effective strategy in principle, but that the effectiveness was not always reflected in actual practice due to the numerous challenges

encountered. Further research in this setting and with this population in other services has been recommended.

9. GENERAL DISCUSSION

9.1. Introduction

In the previous five chapters, various aspects of goal setting for exercise after stroke were considered. The aim of this chapter is to synthesise and integrate these findings to construct an overall picture of this field. An overview of each of the studies is presented first, followed by a discussion of the key findings. The overall strengths and limitations are then identified. The contributions from this programme of work to the field are then presented followed by directions for further research.

9.2. Overview of studies

This programme of work focussed on goal setting in exercise after stroke settings. The overall aim of this work was to investigate the role of goal setting in the uptake and/or maintenance of physical activity of stroke survivors, by designing and evaluating an evidence-based, theoretically-driven goal setting intervention in the exercise after stroke setting. It was hypothesised that person-centred goal setting and goal attainment through principles of self-efficacy and self-regulation would help stroke survivors to uptake and/or maintain physical activity in the long-term. Goal setting for exercise after stroke was identified as a complex intervention, and hence the Medical Research Council (MRC) framework for the design and evaluation of complex interventions was adopted to provide a foundation for the work.

In order to address the above aim, five interlinked studies in line with the MRC framework were conducted. The rationale and aims for each of these studies are outlined next to demonstrate the linking between the studies, followed by a summary of the main findings of each study. Finally the findings are integrated to present the overall results of this programme of work.

9.2.1. **Interlinking between studies**

The first step in the design of a complex intervention was to use the available evidence and theory effectively (Craig et al. 2008). Accordingly, the literature explored in section 2.7.4.4 as part of the background chapter revealed the need for a systematic review to synthesise the evidence for goal setting in stroke rehabilitation. Therefore, a systematic review with the aim of evaluating, critically appraising and synthesising evidence for the effects and experiences of goal setting in stroke rehabilitation was undertaken as the first study of this programme of work (chapter 4). Regarding the use of theory, a thorough analysis of the existing theories on goal setting led to the selection of one theory, namely the Social Cognitive Theory (SCT), for use in this work. This theory was selected because of its strong relevance to goal setting and the rich evidence base supporting the constructs within the theory that were relevant to goal setting.

No well-structured, evidence-based, theoretically driven goal setting intervention that could be used for exercise after stroke was identified from the above systematic review. Therefore, the second study of this programme of work was conducted with the aim of designing such a goal setting intervention (i.e. formal, well-structured, evidence-based, and theoretically driven) (chapter 5). The available evidence (i.e. the findings from the systematic review and the use of an available formal method of goal setting (Canadian Occupational Performance Measure (COPM)) within the intervention), and theory (i.e. the SCT) were used in the development of the person-centred goal setting intervention.

The next stage was to refine the design and content of the intervention, select appropriate outcome measures to evaluate the intervention of study, and validate these measures, if required. Six outcome measures that were related to the intervention and physical activity were chosen. These included: measurement of free-living activity by the activPAL™ activity monitor, 10 metre walk test as a measure of walking speed, Timed Up and Go test as a measure of balance, Stroke Impact Scale as a measure of quality of life, Stroke Self-Efficacy Questionnaire as a measure of self-efficacy, and the

COPM as a measure of goal attainment. Of these, it was identified that the activPAL™ required validation for use in the stroke population. Therefore, a pilot study with the aims of pilot testing the designed goal setting intervention, familiarising the researcher with the use of the outcome measures, and validating the activPAL™ for use in people who have had a stroke was undertaken as the third study of this programme of work (chapter 6).

The goal setting intervention piloted and finalised in the above study was then assessed for feasibility issues as the fourth study of this programme of work (chapter 7). The outcome measures selected within the third study were used to evaluate changes over the course of the study. In relation to the activPAL™, only the variables that demonstrated sufficient validity and reliability in study three were used for analysis in this study. Along with investigation of the feasibility of the goal setting intervention, user experiences of this intervention were also explored.

In order to ensure a more complete understanding of the field and as part of assessing feasibility, it was essential to explore the experiences of exercise professionals who would be responsible for the delivery of this intervention, if it were to be implemented in practice in the future. Therefore, a fifth study with the aim of capturing the perceptions and experiences of exercise professionals in a leisure context regarding goal setting was undertaken (chapter 8).

The main findings of these five studies are summarised next. Where available, the findings are discussed in the light of recently published literature. The implications of these findings to both research and practice are also outlined within these sub-sections.

9.2.2. **Study one**

The systematic review conducted as study one included 17 studies (11 quantitative and six qualitative) involving 614 participants with stroke, along with 43 professionals and

38 carers. The findings synthesised from these studies suggested that goal setting may positively influence perceived performance and goal achievement of patients. However, due to the lack of Randomised Controlled Trials (RCTs) no firm conclusions could be made about the effectiveness of goal setting. Discrepancies were evident between patients and professionals in relation to various aspects of goal setting such as the level of patient involvement in goal setting, how they set goals, types of goals set, and how they evaluated goal attainment. Barriers to goal setting outnumbered the facilitators. Patient education on stroke and goal setting, professional training in goal setting, and improved communication were suggested to overcome these barriers and increase patient involvement in goal setting.

These results were based on a database search until the end of April 2011. The timelines within the project did not allow for a further systematic update. However, a basic update was performed in the Pubmed database using the keywords ‘stroke’ and ‘goal setting’ to identify published articles between April 2011 and November 2013. Only three more relevant articles were obtained from this search (Scobbie et al. 2013, Brown et al. 2013, Levack et al. 2011). The reference lists of these articles were also scanned and no new relevant articles were identified. The findings from those studies were in line with the findings of the systematic review. Therefore their inclusion in the review would have strengthened the findings, rather than modifying the results. In their article, Brown et al. (2013) referenced the published systematic review of this project (Sugavanam et al. 2013) to highlight the similarities of their findings, which further validates the previous statement.

It should be noted that these recent studies were qualitative studies addressing the experiences of goal setting. Although Scobbie et al. (2013) discussed effectiveness of their goal setting intervention, these were only experiences of the perceived benefits but were not evaluated using any standardised outcome measures. This apparent lack of quantitative studies investigating the effectiveness of goal setting per se is a cause for

concern, given the emphasis that is being placed on goal setting in stroke rehabilitation in the recently updated guidelines (NICE 2013).

Through this systematic review of literature, the essential components of an ideal goal setting method were identified (e.g. effective communication), and these were put forth as recommendations for best practice. Moreover, the lack of a standardised method of goal setting in stroke rehabilitation was exposed. The need for high quality studies on the effectiveness of goal setting was also emphasised.

9.2.3. **Study two**

As mentioned above, the lack of a standardised method of goal setting led to the design of a goal setting intervention specifically tailored to exercise after stroke. The recommendations put forth in study one for an ideal goal setting method, such as effective communication between patient and professional, patient education on goal setting, patient involvement in the process, training of professionals in goal setting, and dedicated time for goal setting, were considered within this intervention development. The theoretical constructs from the chosen theory (i.e. Bandura's SCT), such as goal ownership, setting sub-goals, performance attainment, and feedback, were also included in the intervention. Finally, available tools for goal setting were researched, and based on its strengths, the COPM was also included within the intervention. Thus the designed goal setting intervention had the following key components: dedicated time for goal setting, patient education on goal setting, patient involvement in goal setting, goal setting follow-up, and a purpose-designed goal setting workbook.

At the time of the design of this intervention, Scobbie et al. (2009) had identified a need to develop and evaluate a goal setting conceptual and practice framework for use in clinical rehabilitation. Such a framework has been developed since then and trialled for six months in one community rehabilitation team with 23 stroke survivors (Scobbie et al. 2013, Scobbie et al. 2011). Since it was a theoretically driven goal setting framework to

be used in rehabilitation, it was of interest to compare the goal setting intervention designed in the current project to the aforementioned framework.

The goal setting and action-planning framework (G-AP) used the constructs of self-efficacy, outcome expectancies, goal attributes, action planning, coping planning, appraisal, and feedback from Bandura's SCT, Latham and Locke's Goal Setting Theory, and Schwarzer's Health Action Process Approach to develop their framework (Scobbie et al. 2013). That framework comprises of four distinct stages, namely: goal negotiation, goal setting, action planning and coping planning, and appraisal and feedback (Scobbie et al. 2013). Although the intervention designed in this current study did not follow any specific stages, most of the components of the G-AP framework had been included. Only the action and coping planning were not explicitly evident. However, within the goal setting workbook, the participants were asked about the motivators and barriers, and these were discussed during the follow-up sessions. The education component and the inclusion of the workbook did not appear in the G-AP framework and could be viewed as an added strength to the goal setting intervention designed in the current study.

One of the main recommendations made in study one was to identify methods to enable inclusion of people with cognitive and communication problems in goal setting. Therefore, the recently developed SMARTER framework of goal setting for aphasia rehabilitation was of interest (Hersh et al. 2012). The SMARTER acronym stands for Shared (i.e. shared decision making throughout goal setting), Monitored (i.e. continuous evaluation of goals), Accessible (i.e. use of aphasia friendly information tools), Relevant (i.e. goals that are relevant to the patient), Transparent (i.e. alignment of long-term and short-term goals), Evolving (i.e. the recognition that goals may change over time) and Relationship-centred (i.e. collaboration between patient and professional). The SMARTER framework has been proposed to guide a collaborative goal setting process in relation to aphasia rehabilitation. This framework was created based on extensive

interviews conducted with patients (n=50), families (n=48) and speech pathologists (n=34) (Hersh et al. 2012). However, their framework was not theoretically driven and therefore, the underlying principles of goal setting and how goal setting was expected to work is not known. Although developed in aphasia rehabilitation, the developers believe that it could be translated into any rehabilitation setting (Hersh et al. 2012).

The goal setting intervention designed in the current study regarded patient involvement as the most important element. By involving the patients and discussing their own goals, it is believed that the shared and relevant components of the SMARTER framework were achieved. Having regular follow-ups to discuss goal achievement or non-achievement and new goals, addressed the monitored and evolving component of the SMARTER framework. The discussions on goal setting and how short-term goals relate to long-term goals, and provision of a goal setting workbook to document the goals, ensured that the goals were transparent and accessible. The patient and the researcher collaboration during the process of goal setting could be cited as addressing the relationship-centred component of the SMARTER framework.

Overall, the goal setting intervention designed in this study appears to have considered all the components of the recently developed frameworks of goal setting in stroke rehabilitation. Those two frameworks have been developed on different perspectives, as the G-AP framework is theoretically driven, while the SMARTER framework is based on users' needs. By being able to fit the goal setting intervention within these two different frameworks, the strength of the intervention is further highlighted.

This study introduced a novel, formal, well-structured goal setting intervention that was both evidence-based and theory-based. By adopting a systematic approach to the design of the intervention, the components within the intervention were made clear, and the links as to how and why the intervention would work were established.

9.2.4. **Study three**

Study three of this programme of work was conducted with 12 stroke survivors. The goal setting intervention designed in the above study was delivered to all the participants without any difficulty. All participants were able to decide on at least one goal related to physical activity. The researcher's confidence in delivering the intervention was increased through this pilot testing. Positive comments were received for the goal setting workbook. Similarly, no difficulties were encountered with the application of the outcome measures, and fidelity was ensured. Therefore, it was decided that in the next study, all the selected outcome measures, and a similar procedure of goal setting as pilot-tested would be used. However, the validity and reliability of the activPAL™ had mixed results.

The activPAL™ demonstrated excellent inter-device and test-retest reliability for all the variables considered, excluding the test-retest reliability for the number of transitions, which was moderate. The results indicated that activPAL™ was a valid tool to measure time spent in sitting and upright. However, the accuracy of the activPAL™ was reduced when the upright time was separated into time spent in standing (overestimation by the activPAL™) and stepping (underestimation by the activPAL™). The numbers of both transitions and steps were underestimated by the activPAL™. Therefore, it was decided that only the valid and reliable measures of the activPAL™ would be used for the next study (i.e. the time spent in sitting and time spent upright).

This study highlighted the mixed psychometric properties of the activPAL™ when used in people with stroke. This finding led to the discussion of exploring the raw data, adjusting the default settings and modifying the algorithm, to improve the use of activPAL™ in stroke, and was put forth as recommendation for future research.

9.2.5. **Study four**

Four stroke survivors were involved in study four of this programme of work. A mixed method case study approach was followed, rather than a cohort study, due to recruitment problems. Individual case study analysis revealed that participants one and three had positive changes on most outcome measures, while participant four remained the same, or deteriorated. Participant two improved on some measures, but deteriorated on the others. Overall, some elements of feasibility, such as intervention delivery and compliance, were positive, with no adverse effects identified. However, findings regarding other elements of feasibility, such as acceptability of the intervention and the content, were less positive. Qualitative exploration of the participants' experiences identified their perceptions of, and attitudes towards, goal setting. Familiarity with goal setting and personal characteristics emerged as linking themes that led on to the creation of an overarching theme called individualisation in goal setting. Synthesis of quantitative and qualitative data exposed the possible influences of familiarity with goal setting, interest in physical activity, and functional ability on various aspects of goal setting, such as involvement and impact.

The findings from this study raised several questions regarding individualisation required within goal setting, and factors that need to be considered within this individualisation. These are discussed later in this chapter (section 9.4).

9.2.6. **Study five**

In order to explore the views and experiences of exercise professionals involved in exercise after stroke regarding goal setting, three focus groups (n=6 in two focus groups, and n=3 in one focus group) were conducted. Five interlinked interpretive themes emerged from the data, relating to the perceptions of goal setting, the roles of the participants in their respective services, goal setting approaches, challenges to goal setting, and strategies and suggestions for more effective goal setting. Exercise

professionals viewed goal setting positively. However, they felt that its potential effectiveness is not always translated into practice due to the number of barriers encountered. The main barriers included: clients' readiness to change, professionals' lack of knowledge about stroke recovery and prognosis, and organisational-related barriers such as lack of time, and lack of measurement tools. Suggestions to improve goal setting in practice such as selective use of goal setting, increased contact time, and small class numbers were also discussed.

This study was conducted with a population that has not been researched widely, thereby contributing new evidence. By complementing the findings of study four, the findings of this study ensured that a more complete understanding of goal setting in the context of exercise after stroke was obtained.

Having outlined the main findings of the individual studies, key discussion points relating to intervention development and evaluation are presented next, followed by a summary of the findings of this programme of work.

9.3. **Goal setting and the Social Cognitive Theory**

The need to design interventions that are theoretically driven is a major recommendation in behaviour change research (Biddle and Mutrie 2008, Morris et al. 2012, Brug et al. 2005). However, there are also reminders that it is not only sufficient to design interventions based on theory, but it is equally important that the theory is built, refined and improved through discussion in the light of research findings (Brug et al. 2005). Accordingly, the use of Bandura's SCT within this programme of work is discussed. Through its construct of self-efficacy and self-regulation, SCT was used to identify key elements of goal setting, such as goal ownership, setting sub-goals, performance attainment, and feedback that could influence behaviour change. The SSEQ was included as one of the outcome measures in order to be able to measure self-efficacy and

create greater understanding of participants' behaviour in line with the SCT. It appeared that participants with high self-efficacy were able to take better ownership of goals and had better goal achievement than participants who had low self-efficacy; supporting the theoretical basis for the intervention. However, this conclusion is based on a very small sample, and therefore should be interpreted with caution. Within the SCT, Bandura (2005) explains how environmental factors and personal factors play a role in influencing behaviour, and this was apparent in the findings of study four. However, due to the nature of the study design and the small sample, the question of whether one determinant influenced goal setting and the target behaviour (i.e. physical activity) more than the other could not be answered.

9.4. **Goal setting and readiness to change**

One of the interesting findings that emerged from study five was the suggested influence of the client's readiness to change physical activity behaviour on their engagement in the goal setting process. From the discussion, it appeared that patient-centred goal setting may be effective only in participants who are in the appropriate stage of change. Since differences in response to goal setting were observed between stroke survivors in study four, it was of interest to explore whether readiness to change physical activity behaviour may provide some explanation for the differences noted.

The stage of change of a participant is usually determined at the start of any intervention or programme by asking participants to complete a questionnaire (Adams and White 2005). However, the questionnaires that are currently being used vary between studies in terms of the number of questions, the wording used within each question, and the algorithm used to confirm the stages of change (Littell and Girvin 2002, Adams and White 2005, Bulley et al. 2007). Participants' readiness to change was not assessed at the start of study four. This was not considered because the inclusion criterion for referral to EaS specifies that the individual referred must be motivated to take part in the

exercise class. Therefore, during the design of the study it was assumed that all participants would be ready to modify their physical activity behaviour and hence, their readiness to change was not confirmed. In order to explore whether readiness to change could help to explain the differences in response to goal setting, it was necessary to explore the stages of change of participants retrospectively, based on the information they provided during the goal setting discussions, and the data collected.

It appeared that participants one and three were in the 'preparation' stage at the start of the study, as they expressed a keen interest in improving their physical activity. They attended the EaS classes as part of improving their physical fitness and activity during the course of the study. This may be suggestive that these participants had moved into the 'action' stage during the course of the study. It was quite difficult to identify the possible stage of change of participant two. Referral to the EaS service may suggest intention to change, however, in discussions with the researcher it became apparent that physical activity was not a priority for him. He did not attend the EaS classes during the study. However, he had identified it as a goal and mentioned that he would attend the EaS class once his family was with him, although it was not keenly expressed. Based on these factors, it appeared that participant two was in the 'contemplation' stage. Although participant four was referred to the EaS service, which may suggest intention to change, he did not attend any classes during the study. Further, he opted out of the goal setting intervention as he felt that goal setting within the context of physical activity was not relevant to him. He also expressed that he had no intention of improving his physical activity in the interview. Therefore, it could be suggested that this participant was in the 'precontemplation' stage.

Previous literature suggests that individuals in and beyond the preparation stage may benefit more from goal setting (Prochaska and Marcus 1994, Marcus and Forsyth 2003). Based on this, it could be said that goal setting would have been more relevant for participants one and three, and less so for participants two and four. The study findings

reflected the same. Therefore, readiness to change physical activity behaviour appears to influence goal setting in the context of physical activity, based on the study findings.

Although the construct of Stages of Change has been used to explain some of the study findings, it should be highlighted that the idea of placing people in stages and targeting interventions to certain stages is not without criticism (Bandura 2000, Bridle et al. 2005). Bandura (2000) argues that it is important to identify why an individual is demonstrating that behaviour (e.g. why is the person showing no intention to change behaviour?) and choose appropriate strategies to modify that behaviour if needed. He highlights the constructs of the SCT (e.g. risk perception, efficacy belief, and outcome expectations) as key in helping people to change their behaviour. He further argues that interventions should not be targeted based on the Stages of Change, but instead on the determinants of the behaviour (Bandura 2000). In support of the TTM, it should be noted that Stages of Change constitute only one construct of the TTM and for interventions based on TTM to work, it has been recommended that all elements of the theory, including processes of change, decisional balance, and self-efficacy, should be considered (Prochaska and Velicer 1997). However, this does not always appear to be the case in both research and practice. Inappropriate model application and specification were highlighted as factors that could have led to a finding that only limited evidence was available for the effectiveness of stage-based interventions as a basis for behaviour change, in the systematic review of Bridle et al. (2005). A potential mismatch of model application was also noted within the Exercise Referral Scheme in study five (section 8.6.5.1) and is discussed in the next section.

9.5. **Goal setting and Exercise after Stroke Services**

One of the inclusion criteria for referral to the EaS service that participants were recruited from in studies three and four is that the participant should "be motivated to participate in and likely to benefit from an exercise programme". This suggests that

individuals who are not interested in improving their physical activity are not eligible to take part. This criterion may have been included to ensure that the service focussed their work on individuals who are prepared to exercise. However, participants two and four expressed that physical activity was not a priority to them during the goal setting discussions and the interview on experiences of goal setting. Based on the above inclusion criteria, these two participants would not have been eligible for the EaS classes. However, they were referred to the service and this suggests that the referrers did not adequately assess clients' motivational levels and Stages of Change before referral. Another possibility could be that the participants were not aware themselves as to their motivational levels at the time of referral. Further, it is not known whether the motivational levels of participants are assessed or discussed within initial assessments at the EaS service and how these are dealt with. Therefore, it is not clear how this criterion is considered, both by the referrers and the service providers. This lack of clarity calls for more intensive collaboration between the two organisations to ensure more effective service to the targeted population. This would also help in designing studies such as the current programme of work more appropriately in the future.

Going back to the discussion that participants two and four would not have been eligible for referral, it must be noted that based on the study findings and physical activity guidelines, the researcher highlighted that it was more important for these two participants to take up physical activity and improve physical fitness. It should also be recalled that one participant who was referred to the service and was contacted by the researcher in relation to possible participation in the study stated that he was not interested in exercise and declined participation. It could be assumed that this participant did not attend the exercise classes, although it is only an assumption. However, it may be unethical not to refer such participants to the exercise classes because of their lack of interest and readiness to change the physical activity behaviour. On the other hand, if individuals who are not interested in physical activity are referred to the exercise services without consideration of their readiness to change (either by the referrer or the

service provider), they may either not take part in exercise classes (as evident in the above three cases) or drop-out, leading to waste of resources. Thus, it is clear that identification of readiness to change is important, but not sufficient, as discussed below.

The referrer in all these cases must have identified a need for these participants to take up exercise classes and the participants might have actually benefitted from taking part, had they taken up exercise. However, none of them were interested in physical activity and hence, did not take up the classes. Therefore it appears that such services are not optimally attracting the targeted population. This raises the question as to who could help to ensure - and how - that this sub-set of the population (i.e. stroke survivors who may benefit from physical fitness training but do not have the intention to change) do make the transition forward in the stages of change and benefit from taking up physical activity.

It would appear that services such as the Exercise Referral Scheme described in chapter 8.4.3.1 were designed for this purpose. The RSAs stated that the Exercise Referral Scheme was based on the TTM model. In line with this, goal setting should be done only with people in the higher stages of change. However, this appeared not to be the case in practice. According to the RSAs, goal setting was part of the consultation for all clients (a requirement of the service), highlighting a mismatch between theory and practice. This may have contributed to the barriers encountered with goal setting and strengthens the suggestion made by some participants that goal setting should be used selectively, which would be in line with the TTM on which the service was based. That said, it is not known whether these professionals use other recommended strategies, such as education and raising awareness of the associated risks, and regular follow-up, to help the participants move from the lower stages of change to the next levels. Since the focus group discussions were focussed on goal setting, information on this was not collected in the study, however, this would be an interesting area to explore in the future. The use of appropriate strategies for each stage is at the core of the TTM, and for services based on

it, success would depend on this. The finding that goal setting had to be implemented as standard for all clients within the Exercise Referral Scheme, regardless of the stage of change, raises issues for the service. However as mentioned earlier, exploration of this was outwith the aims of the study.

Overall, this discussion highlights that more clarity is required within the structure and procedure of EaS services to ensure that the target population benefits. This would then pave the way for identifying those who would benefit from goal setting and ensure effective goal setting practice. It would also allow those who are identified as not ready for goal setting to engage in strategies which will facilitate this.

9.6. Goal setting - balance between individualisation and standardisation

The individualisation required within goal setting was highlighted in the interviews with stroke participants that related to experiences of goal setting in study four (section 7.5.8.2). This was also evident when discussing feasibility issues within goal setting, such as acceptability and compliance, in the same study (section 7.6.1). The exercise professionals involved in study five also emphasised the flexibility required within goal setting to suit individual needs (section 8.5.4.2). Recent literature has also highlighted this individualisation within goal setting and the flexibility required to accommodate this (Scobbie et al. 2013, Brown et al. 2013). Brown et al (2013, p.5) called for "a more sophisticated, individualised approach to the engagement of patients in goal setting in general and not just to the selection of goals". Based on the experiences of ten stroke survivors, they concluded that a 'one-size-fits-all' approach could not be adopted for goal setting. Interestingly, this was one of the sub-themes that emerged from the interview with participant one in study four (section 7.5.3.4.2). In their evaluation of a goal setting framework, Scobbie et al. (2013) identified that preferences regarding level of involvement in goal setting may differ, not only between individuals, but also within

the same individual at different points in time. Therefore, they put forth that professionals should be flexible in their approach to goal setting (patient-led or professional-led), thereby allowing patients to engage in the partnership in a dynamic way.

Based on all these discussions, it appears that variations need to be implemented within goal setting in terms of an individual's familiarity with goal setting, readiness to change, interest in their target behaviour, presence or absence of cognitive problems, and functioning abilities. If all these variations were to be introduced, then the goal setting intervention would be so individualised that it may not be possible to conduct RCTs, where standardisation of the intervention is of the utmost importance. A very large sample may be required to counteract all the individual factors (Craig et al. 2008). The MRC framework recommendation of choosing a cluster randomised design to counteract individual factors was undertaken by Taylor et al (2012). They investigated the feasibility of using a cluster randomised trial to evaluate a structured goal setting approach using the COPM in four inpatient stroke rehabilitation services. This well-designed study found a large cluster design effect, based on which they explained that a very large sample would be needed to detect a clinically meaningful difference in the selected quality of life measure (Taylor et al. 2012). In the light of the recruitment problems experienced in studies three and four, such large trials may not be feasible in the current exercise after stroke setting. Hypothetically, even if the effects of this intervention were to be demonstrated in a large trial, issues might arise when translating a standardised intervention from research into practice, where individuality is inevitable. Therefore, either way, it is essential that a balance be made between individualisation and standardisation for both research and practice.

In line with this argument, Hawe et al. (2004) have suggested that within research into complex interventions, it may be appropriate to standardise the function and process of the intervention, rather than the individual components, thus allowing for individual

tailoring. They also discuss that the integrity of the intervention should be defined based on the evidence of fit with theory or principles behind the intervention and the expected change process (Hawe et al. 2004). Therefore, for the goal setting intervention designed in this current study, it appears that a controlled trial could be conducted while also allowing individual tailoring. However, sample size requirements may still pose a threat. Further, based on the two services from which the participants were recruited in this programme of work, it appears that EaS services are run differently to one another and for controlled multi-centred trials on goal setting, the required standardisation of the exercise intervention may be difficult. These factors need to be considered when this complex intervention moves into the evaluative phase of the MRC framework for complex interventions.

9.7. **Outcome measures**

As part of intervention evaluation, it is important to consider the outcome measures selected and used in the study.

Objective measurement of free-living physical activity was the primary outcome of interest and the activPAL™ was chosen for this. However, the inability to use all the variables of the activPAL™ was a disadvantage. Use of step counts would have allowed for comparison with the recommended guidelines. Use of the number of transitions would have contributed to a clearer understanding of the physical activity patterns of participants. Therefore, if the activPAL™ is to be considered for use in such interventions, all measured variables should be available for use. Hence improving the psychometric properties of the activity monitor either through algorithm modification or raw data exploration is strongly recommended. A concise literature search was undertaken in the Pubmed database (publication dates: from January 2012 to September 2014), using keywords stroke and activPAL to identify any recently published articles. This search yielded no studies on psychometric properties. However, two most recent

studies that had used activPAL™ in a stroke population were identified (Kunkel et al. 2014, Tieges et al. 2014). To ensure internal validity of the findings from these studies, it is essential that the issues with the psychometric properties of the activPAL™ identified in this programme of work are addressed as a priority

The activPAL™ is only one of many activity monitors available from a wide range of tools to measure physical activity. As explained in chapter 2, section 2.9.1, physical activity could be measured either using subjective methods such as questionnaires and diaries or objective methods such as pedometers and accelerometers. Although accelerometers have several advantages over the other tools such as accuracy, the availability of various models introduces selection issues. In a fairly recent systematic review on physical activity after stroke by Field et al. (2013), 26 studies were included, of which 17 had used an accelerometer. The StepWatch Activity Monitor (SAM) featured the most (11 studies); however, this monitor only provides step counts. No other monitors were used in two or more of the included studies. Although this review may not have included all studies using accelerometers in the stroke population, it highlights that different monitors are available and are being used in this population. Therefore, other alternative monitors to the activPAL™ could be considered. However, similar problems with psychometric properties as experienced with the activPAL™ in this programme of work may arise, and hence a thorough consideration of the psychometric properties of any measurement instrument used is essential. It is also important that the psychometrics are evaluated in a stroke population due to the possibility of a modified gait pattern after stroke that may affect acceleration signals of the accelerometer (refer to chapter 2, section 2.9.1,).

In addition to the psychometric properties, selection of accelerometers depends on several other factors. One such factor is the purpose of using an accelerometer. For example, if time spent in different positions is a key outcome, then the SAM monitor may not be suitable as it provides only step counts. Another growing debate within

accelerometers revolves around the issue of whether movement is measured through a single axis or multiple axes. Theoretically, it would be preferable to use tri-axial accelerometry rather than uni-axial accelerometry. However, studies that compared uni-axial accelerometers with tri-axial accelerometers did not identify any significant differences between them (Hislop et al. 2012, Vanhelst et al. 2012, Robusto and Trost 2012). The activPAL™ used in this programme of work was a uni-axial accelerometer, however, activPALs with tri-axial accelerometer are now available (activPAL^3 ™ and activPAL^3 ™ VT) (PAL Technologies Ltd 2014). There appear to be no studies directly comparing these models, and hence it is not known whether activPAL™ with tri-axial accelerometers would have better accuracy.

The other outcome measures used in this programme of work were the Canadian Occupational Performance Measure, the ten metre walk test, the Timed Up and Go test, the Stroke Self-Efficacy Questionnaire and the Stroke Impact Scale. No difficulties were encountered in the application of any of these measures and all these measures appeared to be relevant to the context of goal setting for exercise after stroke. The inclusion of an additional measure of self-efficacy specific to exercise may be of value for a better understanding of the findings in relation to the selected theory.

9.8. **Goal setting for exercise after stroke – where are we now?**

Based on the findings of this programme of work, goal setting in the field of exercise after stroke appears to be in the early stages. If viewed within the MRC framework, this field is still in the development and feasibility and piloting stages (Craig et al. 2008). The researcher is not aware of any studies exploring the effects of goal setting in this setting. Therefore, the evidence base needs to be established and strengthened. The outcome measures selected for use in this setting seemed relevant and appropriate to this population. However, objective measurement of physical activity using the activPAL™ requires further validation work. To establish the feasibility of goal setting for both

research and practice, several other factors, such as recruitment, referral processes, and inclusion criteria, require scrutiny. Once these factors are understood and standardised to a certain extent, then it would be more feasible to explore and understand goal setting and its potential influences such as familiarity with goal setting and readiness to change. This would then pave the way for conducting exploratory trials, and movement into the evaluation and dissemination stages of the MRC framework (Craig et al. 2008).

9.9. **Strengths and limitations**

The strengths and limitations of each study were discussed in detail in the respective chapters. An overview is provided here.

In-depth exploration of the field of goal setting for exercise after stroke has brought to the forefront various factors that should be taken into consideration for effective use of goal setting. Evidence from the literature, theory, service users' experiences, and service providers' experiences (in this case the exercise professionals who deliver the exercise classes) have all been considered in the development and initial evaluation of the intervention, thereby providing a more holistic approach. Utilisation of different research methods (i.e. quantitative, qualitative, and mixed methods) has helped in the synthesis of information from different perspectives, thereby improving the understanding of this field.

Justification for the study design adopted and the data collection methods that were followed for each study were sound. The procedures for all the studies were standardised and care was taken to reduce any bias. Standardised and validated outcome measures were used throughout. Where possible, experienced researchers and multiple researchers were involved in data collection and analysis. It is believed that all the above measures enhanced the credibility of the findings of the individual studies, and thereby of the whole programme of work.

The key limitation noted in all the data collection studies was the small sample size, which was the result of the recruitment problems faced throughout the course of this work. Reliance on other professionals for recruitment could have led to these recruitment problems. However, the researcher could not be directly involved in recruitment due to ethical issues. Various attempts at improving recruitment within the resources (time and money) available did not yield the expected results. These low numbers have reduced the generalisability of the findings from the quantitative perspective. In terms of qualitative research, data saturation could not be achieved due to low numbers, and achieving this would have strengthened the findings.

Recruitment problems also forced changes in the study design and/or protocol. A cohort study was not possible for study four and therefore, a case study had to be adopted. Along with feasibility, it was initially planned that the preliminary effects of goal setting would be evaluated. However, this was not possible with the low numbers, and hence was not considered. In the same study, a three-month follow-up was planned to explore any carry-over effects of goal setting. However, this was not possible due to the time constraints introduced by extension of the recruitment period, and the time restrictions within the PhD degree programme. For study five, a different recruitment source had to be considered in order to be able to conduct the study. Recruitment problems were also encountered within this source, and only one focus group was conducted with Group Exercise Instructors (GEIs) instead of the planned two focus groups. Hence, experiences shared by this group could not be compared with an identical sub-group as originally planned, which would have strengthened the findings.

In hindsight, it appears a more firm recruitment strategy could have yielded better results. Based on the experience from this programme of work, and on taking into account the recommendations made in the published literature on study recruitment and retention (Taylor-Piliae et al. 2014, Lloyd et al. 2010, Treweek et al. 2010, Ward et al.

2010), the following strategies are being put forth for consideration in the future, when recruiting from similar community stroke exercise services:

(i) Multiple recruitment source sites: As explained in sections 6.5.1 and 7.5.1 , the low number of referrals to the exercise service was cited as one of the reasons for low recruitment. Referral and recruitment to such exercise classes has been highlighted as a barrier in a recent study (Poltawski et al. 2013), suggesting that this is not uncommon. Therefore, having multiple recruitment sites may be essential.

(ii) Multiple methods of recruitment from the same source to reduce the risk of missing potential participants as outlined below:

   a. Approaching potential participants at different points within the referral pathway. For example, in the study four of this work, potential participants were approached both by the referring NHS physiotherapists and the assessing exercise professional within the service.
   b. Advertising the study within the exercise classes and the leisure centres using attractive flyers and posters.

(iii) Involvement of all stakeholders in the development of study protocol and intervention: This involvement may provide a sense of ownership to the study and may promote recruitment.

(iv) Contractual agreements with the recruitment source: Such agreements can ensure more commitment and thereby staff changes may not have such impact on recruitment.

(v) Senior management involvement: Involvement of both management and workforce staff of the recruitment source may be essential to accommodate organisational and staff changes. Measures such as fixed monthly/bimonthly face-to-face meetings to ensure their continuous support and involvement in the proposed work are key to recruitment.

(vi) Study champion: A dedicated person within each recruitment site to promote the study may help in recruitment.

(vii) Professional's time paid for: Where possible, it is important that time spent by professionals in study recruitment is accounted and paid for. This may reduce the common view that study recruitment is an additional workload, and begin to be considered as part of their professional role.

(viii) Incentives for participation: Incentives like a gift card or money voucher may attract potential participants to participate in the study.

(ix) Researcher presence: As part of study promotion, the researcher could visit the leisure centres at the time of the exercise classes and be available to answer any questions from potential participants. This presence may create interest in the study.

(x) Researcher directly involved in recruitment through a clinical role: Where possible, recruitment directly by the researcher rather than an assigned person would improve recruitment. This would only be permitted ethically, if the researcher undertakes a clinical role that would allow him/her to introduce the study to potential participants. For example, in the context of exercise after stroke, the clinical role could be an early counselling about the benefits of exercise.

9.10. **Contributions to the field**

This programme of work has demonstrated that goal setting is a complex phenomenon and a complex intervention. It has highlighted the key components of goal setting that should be included for effective goal setting practice. Further, it has provided a well-structured, theoretically-driven, evidence-based goal setting intervention that can be used for exercise after stroke. The work has also identified several factors that influence goal setting that would require individual tailoring. The importance of linking theory to practice was emphasised both within the concept of person-centeredness in goal setting and provision of exercise after stroke services.

9.11. **Directions for future research**

Specific recommendations for research have been made in the individual chapters. The key areas are identified here:

- An exploratory trial using the goal setting intervention, designed in studies two and three, to evaluate the effectiveness of the intervention needs to be conducted as the next step in line with this programme of work.
- More high quality studies are needed to evaluate the effectiveness of goal setting in stroke rehabilitation.
- Methods to improve the accuracy of the activPAL™ for use in stroke survivors should be investigated.
- Further investigations are needed into factors influencing goal setting, such as familiarity with goal setting, readiness to change the target behaviour, and cognitive problems especially issues with memory.
- The views of exercise professionals regarding goal setting in other services should be explored.
- Perceptions and experiences of goal setting in participants who have been involved in services such as the Exercise Referral Scheme should be explored.

10. **CONCLUSION**

The vicious cycle of low physical activity levels and low physical fitness after stroke has been established, for which physical fitness training is recommended. The increasing robust evidence from this field has highlighted that the benefits of training are not always maintained at follow-up and that most stroke survivors are not meeting the recommended levels of physical activity. In line with this, interventions promoting long-term behavioural change have been called for in order to improve the uptake and maintenance of physical activity after stroke. One such intervention, goal setting, has been explored in depth in this programme of work. The overall aim of this work was to investigate the role of goal setting in the uptake and/or maintenance of physical activity of stroke survivors, by designing and evaluating an evidence-based, theoretically-driven goal setting intervention in the exercise after stroke setting. In order to address the above aim, five interlinked studies were undertaken in line with the MRC framework for developing and evaluating complex interventions.

First, a systematic review of the effects and experiences of goal setting in stroke rehabilitation was conducted (study one) to synthesise and evaluate the evidence for effectiveness and experiences of goal setting in stroke rehabilitation. Based on the review of 17 studies (11 quantitative and six qualitative studies), no firm conclusions could be reached regarding the effectiveness of goal setting due to the lack of RCTs. However, goal setting appeared to positively influence perceived performance and goal achievement of patients. Perceptions of patient involvement in goal setting, the types of goals set, and evaluation of goal attainment differed between patients and professionals. Several barriers to goal setting were identified and these outnumbered the motivators. The importance of educating patients on stroke and goal setting, training professionals in methods of goal setting, and improving communication were the key recommendations put forth to improve goal setting practice. Through this systematic review of the

literature, the lack of a standardised method of goal setting in stroke rehabilitation was exposed.

This led to the second study of this programme of work which aimed to design a well-structured, theoretically-driven, evidence-based goal setting intervention, specifically tailored to exercise after stroke. Three sources were considered in the intervention development, which included: the recommendations put forth in study one for an ideal goal setting method, the constructs of Bandura's Social Cognitive Theory (i.e. goal ownership, setting sub-goals, performance attainment, and feedback), and the inclusion of the Canadian Occupational Performance Measure. Thus the designed goal setting intervention had the following key components: dedicated time for goal setting, patient education on goal setting, patient involvement in goal setting, goal setting follow-up, and a purpose-designed goal setting workbook.

The goal setting intervention developed in study two was pilot tested in study three of this programme of work. Within this study, outcome measures that were relevant to goal setting and the target behaviour of physical activity were selected. However, the activPAL™, which was selected for the objective measurement of free-living physical activity, required validation for use in the stroke population, and hence was validated within this study. The study was conducted with 12 stroke survivors. The designed intervention did not require any changes. The researcher's confidence in delivering the intervention was increased with this pilot testing. Similarly, no difficulties were encountered with the application of the outcome measures, and fidelity was ensured. In terms of the accuracy of the activPAL™ activity monitor, only two variables (i.e. the time spent in sitting and upright) had acceptable validity and reliability properties, and therefore only those variables were considered for the next study.

The feasibility of the goal setting intervention was evaluated as study four of this programme of work. User experiences of the intervention were also explored. This

mixed methods study was conducted with four stroke survivors who were referred to an EaS service. Individual case study analysis revealed positive changes on most outcome measures for participants one and three, mixed findings for participant two and no changes for participant four. With regards to various components of feasibility, positive findings were demonstrated for intervention delivery and compliance, while the findings related to acceptability of the intervention and the content were less positive. No adverse effects were identified. Participants' perceptions of, and attitudes towards, goal setting were identified through the qualitative element of the study. Familiarity with goal setting, and personal characteristics appeared to link the perceptions and attitudes, highlighting the individualisation required within goal setting. Synthesis of quantitative and qualitative data exposed the possible influences of self-efficacy, familiarity with goal setting, interest in physical activity, and functional ability on participant engagement in goal setting.

Qualitative exploration of the experiences regarding goal setting of the exercise professionals involved in another exercise after stroke setting was undertaken as study five of this programme of work, as part of understanding the field of goal setting after stroke. Findings from three focus groups highlighted the gaps between theory and practice regarding goal setting. Although the exercise professionals viewed goal setting positively, they felt that potential effectiveness was not always translated into practice due to the number of barriers encountered. Barriers revolved around clients' readiness to change, professionals' lack of knowledge about stroke, and a number of organisational factors. Suggestions to improve goal setting in practice (e.g. selective use of goal setting) were also discussed.

Comparison and integration of findings from the individual studies highlighted that the individual is the pivot of goal setting. The exploration of various factors that influenced the goal setting process led to identification of a lack of clarity in referral criteria, and a potential mismatch between theoretical model and its application in the exercise after

stroke services involved in this programme of work. Therefore, a call for clarity in referral criteria, referral processes, and roles of the professionals involved was emphasised to ensure that the target population benefits from these services. This may then improve goal setting practices, thereby translating perceived effectiveness into actual practice.

Although this programme of work focussed on goal setting specifically, some of the findings have highlighted the barriers and challenges of engaging stroke survivors in physical activity. With the benefits of exercise after stroke well-established, it is now crucial to understand why stroke survivors experience these barriers, and how these could be overcome to improve engagement in physical activity. As demonstrated in this work, goal setting could be one possible method, however other methods of increasing motivation and engagement need to be explored.

In summary, the aim of designing a goal setting intervention for exercise after stroke settings was achieved. The study findings have contributed, not only to the identification of key components and processes of a goal setting intervention, but have also shown how these components could be incorporated into a structured intervention. A thorough consideration of theory and evidence has highlighted the value of person-centeredness in goal setting, an important consideration for practice. The aim of evaluating the goal setting intervention in exercise after stroke was only partially achieved. Evaluation was possible only in terms of assessing feasibility and exploring experiences. Recognition of the benefits of goal setting, both by the users and providers amidst the various challenges, argues in favour of goal setting and its role in the exercise after stroke setting. Our understanding of goal setting as a complex phenomenon and complex intervention has been enhanced by the recognition of the factors influencing goal setting and by the complexities of these factors. Since these were related to all those involved in this setting (i.e. the stroke survivor, the professional, and the service), the need for a multidimensional approach to understanding and implementing goal setting in exercise

after stroke has been clearly highlighted. Importantly, the pivotal role of the individual in goal setting has been emphasised.

In conclusion, it could be said that Bandura's (2000, p.307) claim that "goals are an interlinked facet of a motivational mechanism and not simply a discrete predictor to be tacked on a conceptual model" was supported by the findings of this programme of work.

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APPENDICES

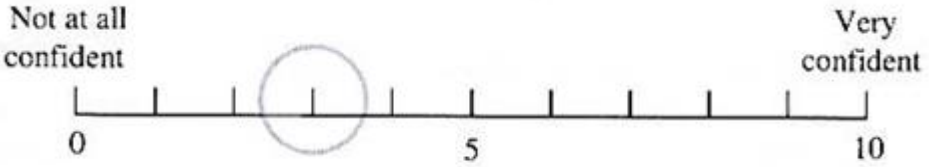
Appendix 1: Stroke Self-efficacy Questionnaire

(Jones et al. 2008)

The STROKE SELF-EFFICACY QUESTION NAIRE

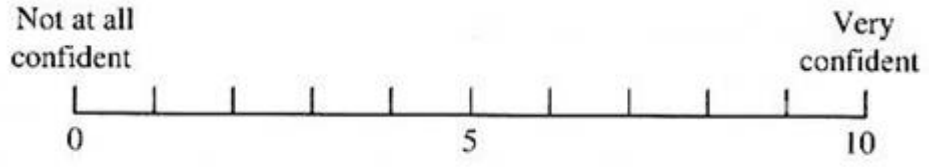
These questions are about your confidence that you can do some tasks that may have been difficult for you since your stroke.

For each of the following tasks, please circle a point on the scale that shows how confident you are that you can do the tasks now in spite of your stroke. Where 0 = *not at all confident* and 10 = *very confident*

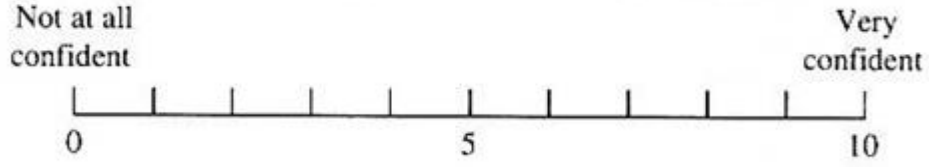


How *Confident* are you *now* that you can

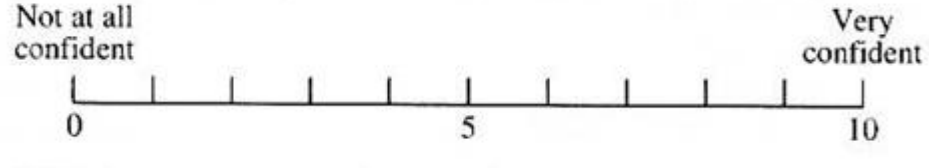
1. Get yourself comfortable in bed every night



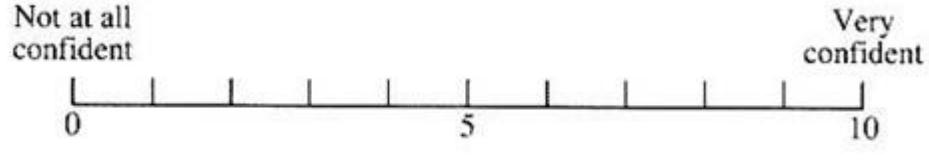
2. Get yourself out of bed on your own even when you feel tired



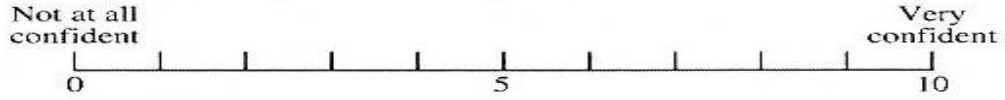
3. Walk a few steps on your own on any surface inside your house.



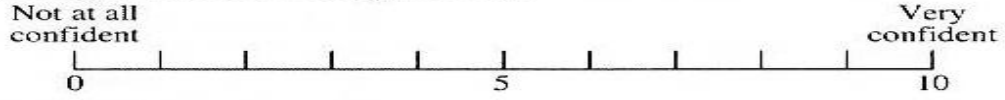
4. Walk about your house to do most things you want.



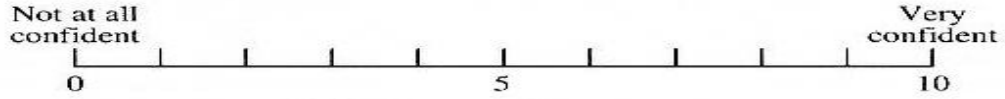
5. Walk safely outside on your own on any surface.



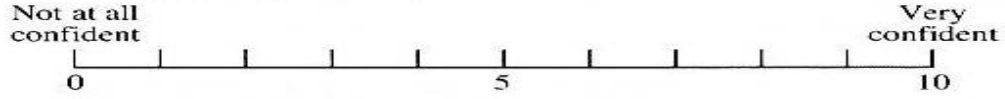
6. Use both your hands for eating your food.



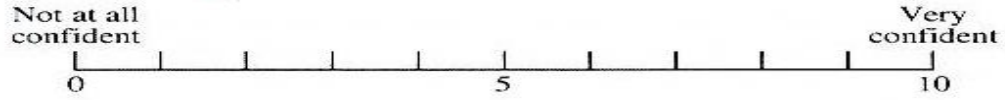
7. Dress and undress yourself even when you feel tired.



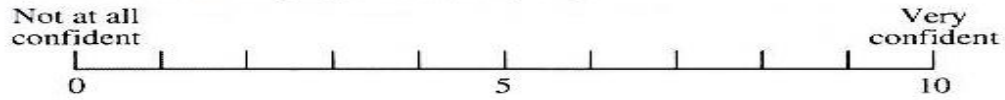
8. Prepare a meal you would like for yourself.



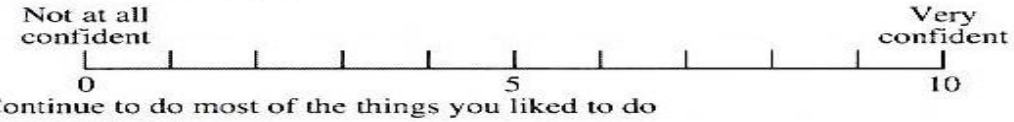
9. Persevere to make progress from your stroke after discharge from therapy.



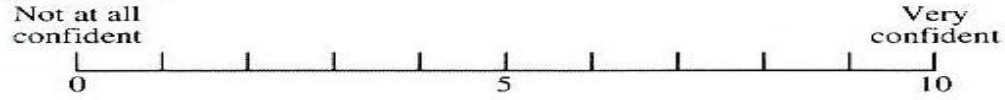
10. Do your own exercise programme every day.



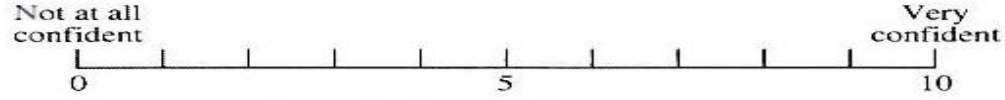
11. Cope with the frustration of not being able to do some things because of your stroke.



12. Continue to do most of the things you liked to do before your stroke.



13. Keep getting faster at the tasks that have been slow since your stroke.



Appendix 2: Stroke Impact Scale

Stroke Impact Scale
VERSION 3.0

The purpose of this questionnaire is to evaluate how stroke has impacted your health and life. We want to know from **YOUR POINT OF VIEW** how stroke has affected you. We will ask you questions about impairments and disabilities caused by your stroke, as well as how stroke has affected your quality of life. Finally, we will ask you to rate how much you think you have recovered from your stroke.

Stroke Impact Scale

These questions are about the physical problems which may have occurred as a result of your stroke.

1. In the past week, how would you rate the strength of your....	**A lot of strength**	**Quite a bit of strength**	**Some strength**	**A little strength**	**No strength at all**
a. Arm that was most affected by your stroke?	5	4	3	2	1
b. Grip of your hand that was most affected by your stroke?	5	4	3	2	1
c. Leg that was most affected by your stroke?	5	4	3	2	1
d. Foot/ankle that was most affected by your stroke?	5	4	3	2	1

These questions are about your memory and thinking.

2. In the past week, how difficult was it for you to...	**Not difficult at all**	**A little difficult**	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
a. Remember things that people just told you?	5	4	3	2	1
b. Remember things that happened the day before?	5	4	3	2	1
c. Remember to do things (e.g. keep scheduled appointments or take medication)?	5	4	3	2	1
d. Remember the day of the week?	5	4	3	2	1
e. Concentrate?	5	4	3	2	1
f. Think quickly?	5	4	3	2	1
g. Solve everyday problems?	5	4	3	2	1

These questions are about how you feel, about changes in your mood and about your ability to control your emotions since your stroke.

3. In the past week, how often did you...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Feel sad?	5	4	3	2	1
b. Feel that there is nobody you are close to?	5	4	3	2	1
c. Feel that you are a burden to others?	5	4	3	2	1
d. Feel that you have nothing to look forward to?	5	4	3	2	1
e. Blame yourself for mistakes that you made?	5	4	3	2	1
f. Enjoy things as much as ever?	5	4	3	2	1
g. Feel quite nervous?	5	4	3	2	1
h. Feel that life is worth living?	5	4	3	2	1
i. Smile and laugh at least once a day?	5	4	3	2	1

The following questions are about your ability to communicate with other people, as well as your ability to understand what you read and what you hear in a conversation.

4. In the past week, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Extremely difficult
a. Say the name of someone who was in front of you?	5	4	3	2	1
b. Understand what was being said to you in a conversation?	5	4	3	2	1
c. Reply to questions?	5	4	3	2	1
d. Correctly name objects?	5	4	3	2	1
e. Participate in a conversation with a group of people?	5	4	3	2	1
f. Have a conversation on the telephone?	5	4	3	2	1
g. Call another person on the telephone, including selecting the correct phone number and dialing?	5	4	3	2	1

The following questions ask about activities you might do during a typical day.

5. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Cut your food with a knife and fork?	5	4	3	2	1
b. Dress the top part of your body?	5	4	3	2	1
c. Bathe yourself?	5	4	3	2	1
d. Clip your toenails?	5	4	3	2	1
e. Get to the toilet on time?	5	4	3	2	1
f. Control your bladder (not have an accident)?	5	4	3	2	1
g. Control your bowels (not have an accident)?	5	4	3	2	1
h. Do light household tasks/chores (e.g. dust, make a bed, take out garbage, do the dishes)?	5	4	3	2	1
i. Go shopping?	5	4	3	2	1
j. Do heavy household chores (e.g. vacuum, laundry or yard work)?	5	4	3	2	1

The following questions are about your ability to be mobile, at home and in the community.

6. In the past 2 weeks, how difficult was it to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Stay sitting without losing your balance?	5	4	3	2	1
b. Stay standing without losing your balance?	5	4	3	2	1
c. Walk without losing your balance?	5	4	3	2	1
d. Move from a bed to a chair?	5	4	3	2	1
e. Walk one block?	5	4	3	2	1
f. Walk fast?	5	4	3	2	1
g. Climb one flight of stairs?	5	4	3	2	1
h. Climb several flights of stairs?	5	4	3	2	1
i. Get in and out of a car?	5	4	3	2	1

The following questions are about your ability to use your hand that was MOST AFFECTED by your stroke.

7. In the past 2 weeks, how difficult was it to use your hand that was most affected by your stroke to...	Not difficult at all	A little difficult	Somewhat difficult	Very difficult	Could not do at all
a. Carry heavy objects (e.g. bag of groceries)?	5	4	3	2	1
b. Turn a doorknob?	5	4	3	2	1
c. Open a can or jar?	5	4	3	2	1
d. Tie a shoe lace?	5	4	3	2	1
e. Pick up a dime?	5	4	3	2	1

The following questions are about how stroke has affected your ability to participate in the activities that you usually do, things that are meaningful to you and help you to find purpose in life.

8. During the past 4 weeks, how much of the time have you been limited in...	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Your work (paid, voluntary or other)	5	4	3	2	1
b. Your social activities?	5	4	3	2	1
c. Quiet recreation (crafts, reading)?	5	4	3	2	1
d. Active recreation (sports, outings, travel)?	5	4	3	2	1
e. Your role as a family member and/or friend?	5	4	3	2	1
f. Your participation in spiritual or religious activities?	5	4	3	2	1
g. Your ability to control your life as you wish?	5	4	3	2	1
h. Your ability to help others?	5	4	3	2	1

9. **Stroke Recovery**

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered from your stroke?

_____ 100 Full Recovery

_____ 90

_____ 80

_____ 70

_____ 60

_____ 50

_____ 40

_____ 30

_____ 20

_____ 10

_____ 0 No Recovery

Appendix 3: Publication – Study one

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REVIEW

The effects and experiences of goal setting in stroke rehabilitation – a systematic review

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Objective: **To systematically integrate and appraise the evidence for effects and experiences of goal setting in stroke rehabilitation.** ***Design:*** **Systematic review of quantitative and qualitative studies.** ***Methods:*** **Relevant databases were searched from start of database to 30 April 2011. Studies of any design employing goal setting, reporting stroke-specific data and evaluating its effects and/ or experiences were included.** ***Results:*** **From a total of 53998 hits, 112 full texts were analysed and 17 studies were included, of which seven evaluated effects while ten explored experiences of goal setting. No eligible randomized controlled trials were identified. Most of the included studies had weak to moderate methodological strengths. The design, methods of goal setting and outcome measures differed, making pooling of results difficult. Goal setting appeared to improve recovery, performance and goal achievement, and positively influenced patients' perceptions of self-care ability and engagement in rehabilitation. However, the actual extent of patient involvement in the goal setting process was not made clear. Patients were often unclear about their role in this process. Professionals reported higher levels of collaboration during goal setting than patients. Patients and professionals differed on how they set goals, types of goals set, and on how they perceived goal attainment. Barriers to goal setting outnumbered the facilitators.** ***Conclusion:*** **Due to the heterogeneity and quality of included studies, no firm conclusions could be made on the effectiveness, feasibility and acceptability of goal setting in stroke rehabilitation. Further rigorous research is required to strengthen the evidence base. Better collaboration and communication between patients and professionals and relevant education are recommended for best practice.**

Keywords: Stroke, goal setting, systematic review

Implications for Rehabilitation

- Communication is key to collaborative goal setting.
- Education and training of professionals regarding goal setting is recommended, especially in relation to methods of involving people with communication and cognitive impairments.
- Educating patients about stroke and goal setting could enhance their participation in goal setting.

Background and rationale

Goal setting is widely recognized as an integral part of rehabilitation, including stroke rehabilitation [1–4], and has been recommended in National Clinical Guidelines for stroke [5,6]. Goal setting is used to enhance patient motivation, adherence and autonomy and to improve their satisfaction with rehabilitation. It is also used to improve task performance, team work and to evaluate progress [7,8]. Several theories underpin goal setting, such as Bandura's Social Cognitive Theory, Locke and Latham's Goal Setting Theory and various Self-Regulation Theories [2,9]. The Social Cognitive Theory discusses the role of self-efficacy in providing motivation, to set and achieve goals, while the Goal Setting Theory emphasizes goal specificity and goal difficulty [2,9]. Self-Regulation Theory highlights the goal oriented behaviour of humans and the emotional consequences of goal attainment [2,9]. Based on these different theoretical backgrounds, various methods of goal setting have been researched and used in rehabilitation [2,10–16]. Patients' and health care professionals' (HCPs) experiences of goal setting have also been evaluated [17–19].

Due to the impact of stroke, the recovery process and prognosis, goal setting for people with stroke is likely to be different from other neurological conditions [12,17]. The

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differences in goals between stroke and traumatic brain injury patients have been highlighted by Phipps and Richardson [12], while Van de Weyer et al. [17] recognized that experiences of goal setting among professionals working with people with stroke may differ from those of professionals working with other neurological conditions. Therefore, it is essential that goal setting is considered specifically in relation to stroke rehabilitation.

With current interest in goal setting and with the growing number of studies, a systematic review to integrate all the evidence underpinning goal setting is important. A systematic review can help to determine how goal setting should be used most effectively in clinical practice, to identify key knowledge gaps, and thus areas for new research. A recent systematic review looked at evidence for goal setting in stroke rehabilitation [20]. That review explored the nature, extent, and effects of the application of the concept of patient-centred goal setting. The authors concluded that patient-centred goal setting is only minimally adopted in goal-setting practice and that its effects have not been evaluated rigorously. However, the results were based on some mixed population studies as well, which makes it difficult to be confident in generalizing the findings to people with stroke. Moreover, the methodological quality of the studies was not discussed extensively in that review. Another review that looked at methods of goal setting in physical therapy, and its application to stroke [21], concluded that there was no single method of goal setting in stroke rehabilitation. A number of reviews have evaluated only the psychometric properties of certain tools of goal setting such as Goal Attainment Scaling (GAS) and the Canadian Occupational Performance Measure (COPM) [22–24]. We believe that both effects and experiences in relation to goal setting should be considered, to be able to provide recommendations for best clinical practice. However, although methods of goal setting and the concept of patient-centeredness have been researched, the authors are not aware of any systematic review that concentrates specifically on the effects and experiences of goal setting in stroke rehabilitation, with the explicit intention to improve current clinical practice.

Objectives

The purpose of this systematic review was to evaluate, critically appraise and synthesize the evidence for the effectiveness of goal setting alongside the experiences of goal setting, such as its acceptability, feasibility and appropriateness, and to put forward recommendations for best practice in stroke rehabilitation.

The two main research questions were:

> "What are the effects of goal setting in stroke rehabilitation on physical function (for example change in performance of activities of daily living) and psychological function (for example changes in self-efficacy and quality of life)?" and
>
> "What are the experiences of people affected by stroke and their treating professionals in relation to goal setting?"

For the review, the definition of goal setting by McGrath and Davis (1992, p. 226) was applied, i.e. "a directive activity incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation [25]". This definition was chosen as it allowed the inclusion of studies where study participants were not included in the process of goal setting or where their involvement was unclear. However, results of the included studies were not interpreted based on this definition.

From the literature obtained, the review also sought to identify barriers and motivators relating to goal setting.

Methods

Design

We included both quantitative and qualitative studies, ensuring that our methods of data synthesis were suitable for the different study types [26]. We used the framework proposed by Thomas et al. (2004) [27], whereby data from quantitative and qualitative studies are extracted and analyzed separately and the findings are then synthesized accordingly to answer the research questions.

Search methods

The complete holdings of Pubmed, Medline, CINAHL, SPORTDiscus, PsycINFO, British Nursing Index, Web of Science, Cochrane, PEDro, Scopus, REHABDATA, EMBASE and AMED were searched from the start of the database until end of April 2011 by one reviewer (TS). Current Controlled Trials (www.controlled-trials.com) and Stroke Trials Directory (www.strokecenter.org/trials/) were also searched until the end of April 2011. The reference lists of the included papers were screened for further relevant publications by the same reviewer.

Keywords

Key words relating to 'Stroke' and 'Goal setting' were used (see Appendix 1 for PubMed search strategy). The same key words were modified to suit the other databases.

Inclusion/exclusion criteria

Our inclusion criteria were (i) studies of any methodological type, as goal setting in stroke rehabilitation is a developing field and it was expected that the number of RCTs may be low (ii) adults (over 18 years of age) affected by any type and duration of stroke, (iii) any setting, (iv) studies involving any form of goal setting (e.g. COPM, GAS) and evaluating either the effects and/or experiences of goal setting, and (v) studies available in English as a full article.

A study was excluded if it met any one of the following criteria: (i) full text of article not available in English, (ii) audit study without any patient data, (iii) not reporting any data on effects or experiences of goal setting, (iv) reporting only carer experiences, (v) quantitative studies with mixed population (including stroke) when stroke-specific data could not be obtained even after contacting the relevant authors, and (v) qualitative design study involving a mixed population (including stroke). Extracting stroke-specific data from these studies would have required analysis of the raw data, which was not within the scope of this review.

Study selection

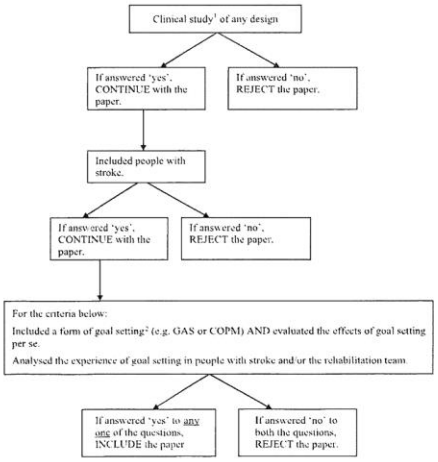
Relevant titles were selected from the full list obtained from the database searches by one reviewer (TS). Duplicates in this list were removed using Reference Manager and the abstracts of remaining studies were scrutinized by the same reviewer who obtained the full text of potentially relevant studies. These studies were then scored independently by two reviewers (TS and FvW or GM) using a decision tree with inclusion and exclusion criteria (Figure 1). Any disagreements regarding study selection were resolved through discussion, after which a final decision on inclusion/rejection was made. A third reviewer (MD) could be consulted in cases where disagreement could not be resolved, however this was not required.

Assessment of methodological quality

The methodological quality of the quantitative studies was assessed by TS and FvW using the Effective Public Health Practice Project (EPHPP) instrument as this encompasses a variety of research designs [28]. The main criteria included: selection bias, study design, confounders, blinding, data collection method, withdrawals and drop-outs. Based on the rating of these individual items, a global rating was provided for the study as either "strong", "moderate" or "weak". The accompanying dictionary was used for the definition for all the criteria and ratings.

Qualitative studies were evaluated by TS and CB using version 2.0 of the critical review form developed by the McMaster University Occupational Therapy Evidence-Based Practice Research Group [29]. Studies were assessed on study purpose, literature, study design, sampling, data collection methods, data analysis method, and conclusions and implications. The section on trustworthiness from the previous version of the form [30], was also added to enhance quality assessment. The accompanying guidelines were used for the definition of each criterion. Based on the findings, the overall rigour of the study on credibility, transferability, dependability and confirmability was assessed. However, for each of these criteria, a judgment was required as to whether it was met or not. To improve the reliability of this judgement, the reviewers agreed that the study should demonstrate at least half of the ideal study characteristics as described in the accompanying guidelines in relation to that criterion. For example: for the criterion "credibility", the ideal would be to have (i) data from a range of participants, (ii) variety of methods to gather data, (iii) journal of reflection, (iv) triangulation and (v) member checking.

Following independent review of each article, findings were compared and any discrepancies were resolved through discussion between reviewers. A third reviewer (MD), although available, was not required.



[1]Clinical studies included a range of studies, from case studies to randomized controlled trials.

[2] Goal setting was defined according to McGrath (1992, p. 226) "a directive activity incorporating the following steps: goal selection, task analysis, assessment, decision, action initiation and evaluation".

COPM: Canadian Occupational performance Measure.

GAS: Goal Attainment Scaling.

Figure 1. Decision tree for selecting abstracts for further scrutiny.

Data extraction

A paper data extraction form was used to extract data on study design, aims; inclusion/exclusion criteria; sample characteristics; setting; goal setting method; any additional methods employed; any interventions used; goal setting outcome measures; any other outcome measures; and results. Studies were categorized as qualitative, quantitative or mixed methods (i.e. a combination of qualitative and quantitative methods) as specified by study authors. Data were extracted independently by two of three reviewers (TS and either FvW or GM); where any discrepancies were detected, differences were resolved through discussion.

Data synthesis

A quantitative meta-synthesis using standardized mean differences [31] was proposed for the quantitative studies. However, this was not possible due to the high variability in design, methods of goal setting and outcome measures employed in the studies. Therefore, the findings from each study were grouped, based on study aims and outcomes. These findings were synthesized and presented as themes. For the qualitative studies, a thematic synthesis was undertaken [32], for which the main findings relating to the research questions were coded. The codes were then analyzed and grouped into themes by the first author (TS) and verified by FvW and CB.

Results

Process of study selection

From a total of 53998 hits, 112 full text articles were selected for analysis, from which 17 were selected to be included in the review (Figure 2).

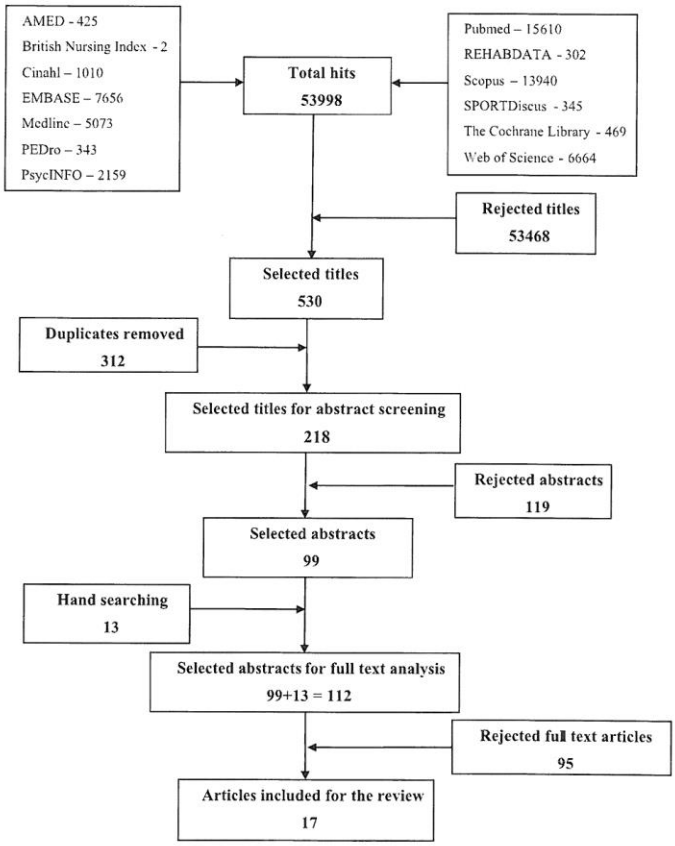


Figure 2. Schematic representation of the study selection process.

Excluded studies

On full text analysis, 95 studies were rejected as five were not in English, 16 were not clinical studies, 11 studies did not include stroke patients, six did not use any goal setting methods, 17 studies did not evaluate effects or explore experiences of goal setting (instead evaluated effects of non-goal setting interventions), authors did not respond to the request for stroke-specific data in nine studies, authors responded that stroke-specific data were not available for two studies, 10 studies had only evaluated the psychometric properties of goal setting outcome measures, eight studies had used goal setting measures such as COPM and GAS but as outcome measures only, and 11 studies were qualitative with a mixed population.

Description of included studies

Of the 17 included studies, 11 were quantitative (of which none was an RCT) [12,13,33–41] and six were qualitative studies [15,42–46]. A total of 614 participants with stroke were involved in the studies along with 43 professionals and 38 carers.

Methodological quality

Of the 11 quantitative studies, only two were rated as "strong" [13,36], five studies were in the category of "moderate" [12,33–35,38] and four were in the "weak" category [37,39–41] on the EPHPP instrument (Table I).

With regards to qualitative studies (Table II),all six studies showed evidence of credibility [15,42–46], four showed

Table I. Methodological assessment of quality of quantitative studies using the Effective Public Health Practice Project (EPHPP) instrument [28].

Author & year	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals & drop-outs	Global rating
Almborg et al. (2008) [33][a]	Moderate	Moderate	Not applicable	Weak	Strong	Moderate	Moderate
Black et al. (2010) [34]	Moderate	Moderate	Not applicable	Moderate	Weak	Strong	Moderate
Brock et al. (2008) [13]	Moderate	Moderate	Not applicable	Moderate	Strong	Moderate	Strong
Folden (1993) [35]	Moderate	Strong	Weak	Moderate	Strong	Moderate	Moderate
Jansa et al. (2004) [36][a]	Moderate	Moderate	Not applicable	Moderate	Strong	Strong	Strong
McAndrew et al. (1999) [37][a]	Strong	Weak	Not applicable	Weak	Weak	Strong	Weak
Phipps and Richardson (2007) [12]	Moderate	Weak	Not applicable	Moderate	Strong	Not applicable	Moderate
Reid and Chesson (1998) [38][a]	Moderate	Weak	Not applicable	Moderate	Strong	Strong	Moderate
Schweizer et al. (2008) [39]	Weak	Weak	Not applicable	Weak	Strong	Strong	Weak
Wilson et al. (2002) [40]	Weak	Weak	Not applicable	Weak	Weak	Strong	Weak
Wressle et al. (2002) [41]	Moderate	Strong	Weak	Moderate	Weak	Weak	Weak

[a]Denotes quantitative studies evaluating the experiences of goal setting.

evidence of transferability [15,42,45,46], five showed dependability [15,43–46] and only two showed evidence of confirmability [15,45].

Definition, theories and methods of goal setting

The majority of the studies did not explicitly define goal setting or state the theories underpinning their goal setting intervention. The Social Cognitive Theory, Goal Setting Theory and Self-Regulation Theory were mentioned in three studies [13,15,43]. Goal setting was approached through different perspectives such as client-centred practice, cognitive rehabilitation and goal attainment. This may have led to the development of different goal setting methods evident in the reviewed studies (Tables III and IV).

Effects of goal setting

Seven studies involving 332 people with stroke and 23 carers used a form of goal setting and evaluated its effects (Table III). As evident from Table III, the study design and method of goal setting varied among the studies. The average age of the participants was 57.7 years and included 202 males and 153 females. The findings have been synthesized and presented as themes below.

Effects on recovery

The effects of goal setting on recovery were explored in four studies (n = 193 participants with stroke) [12,39–41] of which three were of a "weak" quality [39–41] and one study was of "moderate" quality [12] (Table I). In both studies where the COPM was used, performance and satisfaction scores improved significantly at discharge, implying goal achievement and thereby recovery [12,41]. Similarly, goal management training and goal planning approach applied in two single case studies (n = 2 participants with stroke) had positive results for goal achievement, indicating recovery [39,40].

Effects on participants' perceived self-care ability and engagement in rehabilitation

The effects of goal setting on participants' perceptions were analysed in two Quasi-experimental studies (n = 142 participants with stroke) [35,41]. When participants were supported to identify, clarify and express goals, and develop strategies to achieve goals in the domain of self-care in a study of "moderate" quality (Table I), their perceptions of self-care ability improved when compared with participants who did not have this added intervention [35]. However, it was not clear whether perceptions of self-care ability were mirrored by actual behavioural outcomes. In another study of a "weak" methodological rating (Table I), participants who were involved in goal setting were able to recall their treatment goals better, and manage more tasks, compared to a group that did not participate in goal setting [41]. However, the significant differences between the groups at baseline may have confounded the findings. This study would therefore warrant replication in a rigorously designed RCT.

Effects on other variables

Goal achievement was correlated with other variables in two studies (n = 71 participants with stroke and 23 carers) [13,34]; one with a "strong" methodological rating [13] and one with a "moderate" methodological rating [34] (Table I). Based on the findings, the authors concluded that short term goal attainment could be used to measure progress and that the assessment could also aid the treating team in reviewing rehabilitation plans (Table III). However, the results may have been influenced by the short time span between the setting of goals (at two weeks) and discharge (from three weeks). In the study by Brock et al., correlations between goal attainment and perceived level of participation, motor ability, self-efficacy and depression were evaluated [13]. Although, no significant correlations between goal attainment and the above measures were found when assessed prior to discharge, goal attainment showed a moderate to strong correlation with these measures at six months post-discharge (Table III). Therefore, the authors speculated that, instead of factors such as depression and self-efficacy at discharge influencing goal attainment at a later stage, goal attainment itself might effect positive changes in mood, physical ability and self-efficacy. However, these results needs to be confirmed with a bigger sample, and validated outcome measures.

Experiences of goal setting

Ten studies, involving 282 participants with stroke, 15 carers and 43 HCPs, explored experiences of goal setting (Table IV).

Table II. Methodological assessment of the quality of qualitative studies using McMaster University critical review form [29].

	Sampling						Descriptive clarity						Triangulation						Overall rigour					
	Study purpose	Literature review	Study design	Theoretical perspective	Methods used	Purposeful selection	Sampling until redundancy	Informed consent	Site	Participants	Role of researcher & participant relation	Identification of assumption of researcher	Procedural rigour	Inductive data analysis	Findings consistent with data	Reporting of decision trail and rules	Transforming codes/memes/data into theoretical constructs	Theoretical connections	Source	Methods	Researchers	Theories	Member checking	Appropriate conclusions	Contribution for future research	Credibility	Transferability	Dependability	Confirmability
Hale (2010) [42]	Yes	Yes	ID	No	int, ccn, npo	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	No	No
Laver et al. (2010) [43]	Yes	Yes	nad	No	int, ccn	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes	No
Lawler et al. (1999) [44]	Yes	Yes	GT	Yes	int, sr	Yes	No	Yes	No	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No
Leach et al. (2010) [15]	Yes	Yes	nad	No	e-mail int	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mew and Fossey (1996) [45]	Yes	Yes	Eth	No	obs, int, fn	Yes	n/a	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wressle et al. (1999) [46]	Yes	Yes	GT	Yes	int, in-d	Yes	Yes	nad	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	No

Abbreviations: ccn: clinical case notes; fn: field notes; GT: grounded theory; Eth: Ethnography; ID: interpretative description; in-d: intervention diaries; int: interviews; nad: not addressed; n/a: not applicable; npo: non participant observation; obs: video & audio observations; sr: analysis of structured records.

Table III. Overview of studies included in this review evaluating the effects of goal setting as an intervention.

Author (year) Country	Study design	Sample size	Goal setting method & details Measures collected when?	Findings related to goal setting
Black et al. (2010) [34] Australia	Prospective observational study	Total sample size n = 54 PWS n = 26	Goals set in various domains with contributions from all rehabilitation team members. Goal achievement scored as "exceeded", "achieved" or "not achieved". Measures taken at two weeks after initial team meeting and at discharge.	Significant correlations between short-term goal achievement at two weeks post initial team meeting and achievement of discharge goals for global function ($\rho = 0.67$ $p < 0.001$). For those returning home, correlation between predicted and actual length of stay: $r = 0.71$, $p < 0.001$. Significant correlations between adherence to predicted length of stay and achievement of short term goals in transfers ($\rho = 0.45$, $p = 0.04$), PADL ($\rho = 0.44$, $p = 0.04$) and global function ($\rho = 0.62$, $p < 0.01$).
Brock et al. (2008) [13] Australia	Prospective follow-up cohort study.	Baseline: PWS n = 59 Follow-up at six months post discharge: PWS (from original sample) n = 45 & C n = 23.	GAS, using median instead of weighted scores. Patients and carers involved in GS and all team members trained in GS. Measurements done prior to in patient discharge and at six months post-discharge.	Goal attainment at six months post-discharge: 21/45 cases (47%) achieved all goals; 16/45 cases (36%) made some progress; 8/45 cases (17%) made no progress or deteriorated. Moderate correlation between goal attainment and LHS (between -0.45 and -0.51, $p < 0.005$) at six months post-discharge on LHS ($-0.52 \leq rs \leq -0.47$, $p<0.005$). Significant correlation at six months post-discharge and not at discharge between goal attainment and FIM-Motor ($rs = 0.55$, $p < 0.001$), SUPPH-coping ($rs = 0.43$, $p < 0.005$), CES-D ($rs = -0.43$, $p < 0.005$).
Folden (1993) [35] USA	Quasi experimental study.	Baseline: PWS n = 90 Post test (14 to 18 days after baseline): PWS (from original sample) n = 68 (34 in each group)	GS only in EG. Intervention protocol involved helping the participant identify, clarify expressing goals in measurable terms, identify and list self-care assets needed and self-care deficits that must be overcome to meet goals, identify strategies to meet goals. Four visits at least two days apart over a four week period in addition to regular rehabilitation. Control group received regular rehabilitation but had no contact with the researcher. Pre test measurement three to four days after admission to unit and post test 14 to 18 days after administration of the pre test.	EG (mean score 127.74) improved significantly more than CG (mean score 115.18) in the perception of self-care ability as measured on ESCA ($F = 33.36$, $p < 0.001$).
Phipps and Richardson (2007) [12] USA	Retrospective cohort study.	Total sample size n = 155. PWS n = 117 in which n = 53 right hemisphere stroke and n = 64 left hemisphere stroke.	COPM. Patients along with the treating team involved in the GS process. Family member or translator involved if required. Therapists trained and assessed on the COPM. COPM scores calculated at the start of the OT intervention and at discharge.	Goal attainment: Significant changes on COPM ($p < 0.05$) post intervention: change in mean COPM-P (SD) – Right stroke: 3.71 (2.12), Left stroke: 2.85 (2.14); change in mean COPM-S (SD) – Right stroke: 4.07 (2.41), Left stroke: 3.00 (2.31) Right stroke had significant increase in COPM-S than left stroke ($p = 0.03$).
Schweizer et al. (2008) [39] Canada	Uncontrolled single case study as part of RCT.	PWS n = 1	Goal Management Training (GMT). GMT uses task breakdown, self-prompting to halt automatic behaviours that impede progress, resuming control and monitoring progress with a task, to overcome disorganized behaviour. GMT consisted of 2-h sessions once per week for 7 weeks. Measurements taken at baseline (127 days post injury), post intervention (after seven weeks – 218 days post injury) and four months after intervention (322 days post injury).	Generic goal of GMT: to reduce disorganized behaviour stemming from executive and attentional impairments. Improvements on a range of neuropsychological tests, including memory, verbal learning, and attention tasks. Return to work.
Wilson et al. (2002) [40] UK	Single case study, pretest-posttest design.	PWS n = 1	Goal Planning. A total of 12 goals were set, tailored to the individual covering all domains of the WHO ICF. Long term goal was broken down into one or two short-term goals. Goals agreed between participant, spouse and members of rehabilitation team.	Goal attainment: all goals achieved – although cognitive impairments persisted, and performance on many of the goals identified lower than normal.

(Continued)

Table III. *(Continued).*

Author (year) Country	Study design	Sample size	Goal setting method & details Measures collected when?	Findings related to goal setting
			Measures taken at start, throughout, and end of the 100-day intervention and on three occasions afterwards up to one year after end of intervention.	Achievements at discharge were maintained until 1 year post intervention.
Wressle et al. (2002) [41] Sweden	Experimental design with experimental (COPM) and control group.	Total sample size n = 206 PWS n = 50 in experimental group (of which n = 28 interviewed) & n = 24 in control group (of which n = 11 interviewed)	Goal setting using COPM in the EG. Patients and therapists involved in the GS process Measures taken on admission and prior to discharge. Structured interviews within 2–4 weeks after discharge.	No significant differences between groups on the Klein-Bell ADL scale and COVS. Significant improvement on COPM-P ($Z = -5.935$, $p < 0.001$) and COPM-S ($Z = -5.775$, $P < 0.001$) scores on discharge in the EG. Average change score for COPM-P was 3.13 and 3.29 for COPM-S denoting clinical significance. Interview findings: agreement that goals were formulated for treatment (82% in experimental group, 27% in the control group); recall of own treatment goals (72% in experimental group, 36% in the control group); perceived active participation in goal formulation process (46% in experimental group, 9% in the control group); managing more tasks compared to before rehabilitation (75% in experimental group, 9% in the control group).

Abbreviations: C: carer/ family; CES-D: Centre for Epidemiologic Studies Depression Scale; CG: control group; COPM: Canadian Occupational Performance Measure; COPM-P: Performance dimension of the COPM; COPM-S: Satisfaction dimension of the COPM; COVS: Clinical Outcome Variables; EG: experimental group; ESCA Scale: Revised version of the Exercise of Self-care Agency scale; FIM: Functional Independence Measure; GAS: Goal Attainment Scaling; GS: goal setting; HCP: health care professionals; LHS: London Handicap Scale; (M)MMSE: (Modified) Mini Mental State Examination; OT: Occupational therapy/ therapist; PADL: Personal ADL; PT: Physiotherapy/ therapists; PWS: person (s) with stroke; SALT: Speech and Language Therapy/therapist; SUPPH: Strategies used by People to Promote Health; TBI: traumatic brain injury.

Table IV. Overview of studies included in the systematic review, exploring the experiences of goal setting.

Author (year) Country	Study design	Sample size	Data collection method (goal setting method, where relevant) & details	Findings related to goal setting
Almborg et al. (2008) [33] Sweden	Quantitative design: Cross-sectional study	PWS n = 188	GS as part of discharge planning. Patients' Questionnaire on Participation in Discharge Planning data collected 2–3 weeks after discharge.	Participants (in %) who perceived participation in discussions on: treatment goals with physician: 29%; goals of further care/ services after discharge: 17%; goals of further rehabilitation after discharge: 15%. Factors associated with greater perceived participation in needs assessment and GS: lower level of ADL at 5 days, higher level of ADL at 2–3 weeks (most important factor), education higher than elementary, longer hospital stays.
Hale (2010) [42] New Zealand	Qualitative design: Interpretative description.	PT's n = 4	Method of GS: GAS. The PTs were new to GAS and received training before the start of the study. Multiple data sources – interviews over telephone and in person, PTs' case notes, researcher's field notes and non participant observation.	(i) Enthusiastically cautious on using GAS – beneficial, not appropriate for all, reliability of GAS questioned, best used with a standardized outcome measure; (ii) Another useful tool in the box of interventions- to guide treatment, to set patient-centred goals, use goals to encourage, motivate and prompt patients; (iii) Time consuming - more time required to set goals; (iv) Not easy to set goals - in case of rapid progress, cognitive or communication disorders, patient's lack of motivation or reluctance to set goals.
Jansa et al. (2004) [36] Slovenia	Quantitative design: Cohort study with pretest-posttest measures.	PWS n = 80, of whom n = 29 used the COPM.	Method of GS: COPM, COPM undertaken in: n = 26/80 PWS at admission and discharge; n = 3/80 PWS at discharge only; n = 2 C involved in interview.	Client priorities followed only in 36.25% of the total sample (29 out of 80). Goal attainment: changes in mean COPM scores (range): COPM-P: +2; from 3.6 (1–8) to 5.6 (3–10) (p = 0.084); COPM-S: +2; from 4.1 (1–10) to 6.1 (3–10) (p = 0.006). Other findings: Not possible to complete the COPM with all participants, due to cognitive, emotional and communicative difficulties (proportion not reported).

(Continued)

Laver et al. (2010) [43] Australia	Qualitative study with semi-structured interviews.	PWS n = 15	Semi-structured interviews conducted by the researcher with participants when in the acute hospital care, during sub-acute rehabilitation and six months after stroke. Interview on: setting goals, meaning of the goals, key things that the patients aims to improve, whether they were ready to set goals at each stage in hindsight.	(i) Participant goals - difficulty understanding 'goal' terminology, broad goals rather than specific; (ii) Involvement in GS- unable to recall discussion of specific goals discussed with therapists, most agreed with documented goals and that goals were set with them collaboratively, all participants had at least one goal documented by clinicians in the progress notes; (iii) Readiness to set goals - varied greatly between individuals, 7/15 felt not ready to set goals in acute phase others were ready (6 /7 were able to give at least one goal statement in the acute phase), varied response when participants were asked at 6 months after stroke as to the best time to set goals, 9/15 lacked knowledge around stroke recovery and unsure as to what goals would be realistic.
Lawler et al. (1999) [44] UK	Qualitative study with semi-structured interviews in context of main study (RCT).	PWS n = 30 C n = 15 Specialist nurses n = 5.	Information gathered: semi-structured interviews with PWS and C; analysis of structured nurses' records; semi-structured interviews with nurses. The authors conducted the interviews.	Nurses' perceptions – Variable acceptance of the term "goal", some reluctant to use it, due to its association with formality, simplicity and fixed nature; Agreement on the individual nature of goals, a collaborative approach, the importance of appropriate goals; Difficulties with setting (achievable) goals; Perceived danger of interfering with positive relationship; Tension between establishing a supportive relationship and motivating patients, and the reality of achievable goals. PWS and C perceptions - formulated hopes rather than specific goals.
Leach et al. (2010) [15] Australia	Qualitative design with semi-structured interviews.	Treating therapists n = 8 (n = 2 SALT; n = 3 OT, n = 3 PT) PWS n = 5 only as case examples	Qualitative, semi-structured email interviews, based on questionnaire with seven open questions. Framework approach. Email exchanges continued until all necessary data had been obtained and clarified.	GS approaches: Therapist controlled (10/15), Therapist led (4/15), Patient focussed (1/15). Number of barriers outnumbered facilitators. Facilitators to patient-centred GS: generally seen as beneficial in terms of increasing patient motivation and therapist effectiveness, enabling a more holistic rehabilitation process. Barriers to GS: patient factors: communication impairments, depression and grief reactions, unrealistic expectations, lack of insight, cultural and linguistic diversity; therapist factors: lack of time; contextual factors: difficulty setting participation-based goals in sub-acute setting.
McAndrew et al. (1999) [37] USA	Quantitative design: Quasi-experimental between group design.	PWS n = 10 OT n = 10	GS method: not stated. Questionnaires consisting of matched items developed specifically for the study (one each for patients and therapists). Questions addressed primary roles, interests, hobbies, daily routines, assistance available at home, home environment, and the GS process. Responses to questions were rated on a 5 point Likert scales.	For 9/10 items, the patients' perceptions of the level of collaboration were lower than that of the therapists. Differences statistically significant only in regards to discussion of interests and hobbies ($t = 3.16$, $df = 18$, $p < .05$), therapists' awareness of assistance available upon discharge ($t = 3.49$, $df = 18$, $p < .05$) and explanation of the tasks, activities or exercises performed ($t = 3.28$, $df = 18$, $p < 0.05$). Absolute agreement between PWS &OT on whether important activities were included in the goals.
Mew and Fossey (1996) [45] Australia	Qualitative single case study.	OT n = 1. (PWS n = 1 as case example)	GS method: COPM COPM interview (40 minutes) between OT and patient recorded (video and audio). Also observed by author from another room and field notes taken. A week later, author had a discussion with OT reflecting on clinical reasoning and the COPM interview (audio taped).	Collaboration between therapist and client is key in the process of GS. The extent to which the patient is involved in their GS process may vary across the stages of the GS process (i.e. defining problems, establishing priority and negotiating goals). Inconsistencies in the collaborative approach with a patient and inability to clearly explain the link between the therapist's and the patient's goals may affect the patient–therapist relationship.
Reid and Chesson (1998) [38] UK	Quantitative case studies Acceptability and feasibility study	PWS n = 5 (of 16 PWS, goals were set only for 5 because of many being dysphasic and staffing problems).	GS Method: GAS. Therapists' goals: Treating PT assessed the patient and set goals separately using GAS. Patients' goals: PWS set goals separately with the help of a different PT who was not involved in the treatment and blinded to treating PT's goals. On GAS completion, the patient read and accepted them.	PWS identified 23 goals, PTs identified 28 goals. Broad agreement between PWSs and PTs re. main problems for intervention. PWS tended to focus on function, PTs tended to focus on underlying impairments. Goal attainment: PWS reported no improvement in 11/23 goals; PTs reported no improvement in 6/28 goals. Two case studies are reported to highlight differences in GS process and outcomes - Goal identification: some goals were identified by PWS that were not identified by the PT, and vice versa; Goal scaling differed; Level of goal attainment differed.

(Continued)

Table IV. *(Continued)*

Author (year) Country	Study design	Sample size	Data collection method (goal setting method, where relevant) & details	Findings related to goal setting
Wressle, Oberg and Henriksson. (1999) [46] Sweden	Qualitative design with interviews.	The GS component of the paper comprised n = 30 interviews with: PWS: n = 5, PTs: n = 5, OTs: n = 5 & Physicians: n = 5	From this paper, only the information pertaining to GS was selected, which involved the analysis of 30 interviews. The interviews were conducted by the author at an early stage of rehabilitation process and within 2 weeks of discharge. The interviews focussed on patient's pre-stroke situation, the falling ill period, the rehabilitation interventions, the goals and the method for outcome measuring.	Goals selected by PWS focused on:ADL, attaining pre-stroke status, living at home, regaining mobility and social integration. One patient had no goals. Goals selected by HCPs concentrated on disability and handicap. There were no impairment-orientated treatment goals although there were impairment-orientated interventions: Formulations that did not match the ICIDH were those related to motivation, feelings of security and belief in oneself. Goal attainment - PWS tended to compare their current status with that before stroke; Rehabilitation professionals compared the patient's current status with goals set.

Abbreviations: ADL: Activities of Daily Living; C: carer/ family; COPM: Canadian Occupational Performance Measure; COPM-P: Performance dimension of the COPM; COPM-S: Satisfaction dimension of the COPM; EG: experimental group; GAS: Goal Attainment Scaling; GS: goal setting; HCP: health care professionals; (M)MSE: (Modified) Mini Mental State Examination; OT: Occupational therapy/ therapist; PT: Physiotherapy/therapist.

Four were quantitative [33,36–38] and six were qualitative [15,42–46]. Due to the varied design and outcomes of the quantitative studies, a quantitative synthesis was not possible. Therefore, the main findings of these four quantitative studies were integrated with the themes that emerged from the analysis of qualitative studies and are presented together.

Differences within goal setting – patients versus professionals

Eight studies (n = 253 participants with stroke, 15 carers and 35 HCPs) of varying methodological ratings discussed differences within goal setting between patients and professionals [15,33,37,38,42–44,46]. The quantitative studies had moderate to weak methodologies, while the qualitative studies – excluding the study of Leach et al. – lacked confirmability (Tables I and II)]. Patients were often unclear about the meaning of goal setting and their role in this process [33,37,38,43]. Therefore, they had a poorer perception of their participation in goal setting as well as the collaborative process itself, when compared with the positive perceptions of professionals regarding all aspects of goal setting [37,38,42,44]. One reason for the lower level of participation could be that patients were not ready to set goals at that particular stage [43].

Patients tended to be more optimistic than therapists regarding the expected level of outcome and this led to patients perceiving lower goal attainment [38,44]. The lower perception of goal attainment among patients could also be attributed to the finding that rehabilitation professionals compared the patients' current status with their most recent post-stroke status, in contrast to the patients, who compared their current with their pre-stroke status [46].

The differences in perceptions of goal setting between patients and professionals could relate to the goal setting approach used. In the study by Leach et al., only one therapist (of 15) fully involved patients in all aspects of goal setting; ten involved patients to some extent; while four professionals drove the process themselves, with limited patient interaction [15].

The patients and professionals also differed in the types of goals set [15,38,43–46]. Patients formulated hopes rather than goals, and any goals formulated tended to be broad, rather than specific [43,44]. While patients tended to formulate more general, functional goals for the longer term, therapists tended to identify the underlying short-term impairment problems. The goals the professionals set were specific and related to their respective disciplines [46].

Goal setting and the patient–therapist relationship

The influence of goal setting on the patient therapist–relationship was discussed in two studies (n = 30 participants with stroke, 15 carers and 6 HCPs) [44,45], one of which had a higher risk of bias than the other (Table II). The nurses in the study by Lawler et al. perceived a risk of interfering with the positive relationship developed with the patient by imposing goals on them [44]. In the study by Mew and Fossey, a negative impact on the patient–therapist relationship resulted due to inconsistencies in the collaborative approach with the patient and an inability to clearly explain the link between the therapist's and the patient's goals [45]. These studies highlighted

that collaboration between therapist and patient in the goal setting process is essential for goal setting to have a positive influence on the patient–therapist relationship.

Applicability of goal setting

The application of formal methods of goal setting (COPM and GAS) for stoke rehabilitation was evaluated in four studies (n = 34 participants with stroke and 5 HCPs) of varying methodological strengths [36,38,42,45] (Tables I and II). It was discussed that these specific methods helped professionals to identify the differences in their goals compared to those of patients [38,45]. However, the four studies raised concerns that goal setting could not be applied to all participants due to various barriers which are discussed below.

Barriers and facilitators

Four studies identified motivators to goal setting [15,34,36,42]. Professionals considered goal setting to be a tool that enabled them to achieve patient-centred treatment, since goal setting was seen as providing an opportunity for patient participation in problem identification, goal prioritization and evaluation of goal attainment [15,34,36,42]. Goal setting was also seen by professionals as increasing patient motivation for therapy and maximizing the impact of therapists' time [15].

Barriers to goal setting were discussed in six studies [15,35,42,43,45,46]. All these barriers were identified by professionals who were either participants in the study or authors of the respective study. Interestingly, the number of identified barriers was greater than the number of facilitators. To obtain an overview, the barriers are categorized as those relating to the patient, treating team and organization, as presented in the study of Leach et al. [15]

Patients' cognitive and communication impairments were identified as the main barriers to goal setting. The HCPs felt that these difficulties may prevent patients from participating in goal setting and that it would be difficult and time consuming to set goals with them [15,42]. It is noteworthy that, of the 17 studies included in this review, only two had included participants with these difficulties [13,40]. Brock et al. mentioned that their speech pathologists had made small modifications to the questionnaires, simplifying language and creating large type visual aids to ensure the participation of people with communication and cognitive difficulties in their study [13]. However as acknowledged by the authors, the validity and reliability of this modified version was not tested [13]. On the other hand, how the issues were handled to ensure patients' participation in goal setting was not explained the study of Wilson et al. [40]. Nine studies stated that people with communication or cognitive disorders had been excluded [12,33,35,37,38,41,43,45,46]. In one study, 51 of 80 (63.8%) patients were not able to complete the COPM [36], while in another, 66 of 321 (20.5%) patients were excluded [33] due to cognitive or communication problems. These figures highlight that cognitive and communication impairments are major barriers and that further work is needed to determine how best to include these patients in the goal setting process.

The other patient-related barriers of goal setting included: (i) lack of understanding of the rehabilitation process, (ii) lack of knowledge and understanding regarding the consequences of stroke and realistic outcomes, (iii) lack of motivation and reluctance to set goals, (iv) depression, (v) lack of readiness to set goals, and (vi) psychosocial issues [15,36,42,43,46].

As for the HCPs perceptions of barriers to goal setting, the main issue was the increased demands on their time due to the difficulty in encouraging patients to express their own goals, especially in those with cognitive and communication issues. Further barriers included: failure to consistently convey the meaning of therapy goals to patients and explain how they related to the patient's own goals; cultural differences between patient and therapist; inability to address goals that require a different setting; difficulty scheduling goal setting meetings between disciplines; and doubts regarding reliability of tools used for goal setting [15,35,42,45].

Shift working of key workers and other professionals, increased work load, and staffing issues were identified as key organizational barriers [15,42].

Discussion

This systematic review aimed to synthesize evidence pertaining to the effects and experiences of goal setting in stroke rehabilitation.

No firm conclusions could be arrived at regarding the effectiveness of goal setting, as there were no RCTs and the methodological quality of most of the studies was weak to moderate. The average age of participants in these studies was also below that of the general stroke population. Despite the limitations, the observational studies suggested that goal setting appeared to positively influence patients' perceptions of participation and self-care ability and may impact on their performance and goal achievement. Randomized trials with robust methodology are now required to substantiate these suggestions. Patients were often unclear regarding their role in the goal setting process and did not participate fully, whilst professionals seemed to be more positive about the level of collaboration with their patients in goal setting. There were discrepancies between patients and professionals in terms of how they set goals, the types of goals set and how they evaluated goal attainment. Moreover, several barriers were identified by professionals in relation to the goal setting process, which outnumbered the facilitators.

The results of this review are comparable to those of Rosewilliam et al. [20]. However, the present review appraised the evidence regarding the effects and experiences of goal setting separately and integrated this evidence, which is a necessary step towards making recommendations for best practice. Moreover, both reviews have included different studies, with only five in common. By including studies with stroke-specific data only, one can be more confident in generalizing the findings to stroke rehabilitation. Comparatively, the methodological quality of the studies has been considered in greater detail, which adds to the overall quality of the current review. The results also support the conclusions of Kamioka et al. and Levack et al. in that there appears to be no single method of goal setting in stroke rehabilitation [21,47].

The results of the review were compared with the studies that were excluded either because of the unavailability of stroke-specific data [11,48–57], or the study being a qualitative design with a mixed population [17–19,58–65]. Overall, the comparison showed similar results with the effects, experiences and barriers of goal setting.

Ideally the goal setting methods of each study would have been compared against an ideal, or standard, to demonstrate the strengths, weaknesses and missing elements. Although several researchers have made recommendations on features of an effective goal setting method, a recent consensus meeting on goal setting showed that there is no published goal standard for goal setting [2]. Furthermore, even when formal methods of goal setting (e.g. GAS) were used, researchers modified the procedures, thereby making comparisons difficult [13]. Similarly, there appears to be no standard theoretical structural framework for goal setting in rehabilitation and information has been drawn from various theories [2,9]. As noted earlier, this may have contributed to the variation in the interpretation of goal setting, and the diversity in the methods of goal setting, which hampered the pooling of results. The lack of a standard theoretical structural framework for goal setting, and a standard method of goal setting, was evident in the studies included in the review and in the findings of this review as discussed below.

Although authors stated that participants with stroke were involved in the goal setting process in some studies, the extent to which they were involved was not explained in sufficient detail anywhere [12,13,34,35,39–41]. This raises concerns, as it emerged that patients were often unclear regarding their role in goal setting and that participation was often limited [33,37,43–45]. The latter was also reflected in studies that were not included in the review, highlighting that it is not uncommon [60,63,65–67]. Apparently, HCPs' claims that they fully involve patients in goal setting are misperceptions in some cases [66–69]. Increasing patient involvement may facilitate patient-centred practice by moving away from a therapist-led goal setting approach (which is more common), towards a patient focussed or patient-centred goal setting approach [15,70,71].

Goal setting can influence a therapist–client relationship both positively and negatively. Conflict that affects the relationship may arise due to the differences in the goals between patients and therapists [15,38,43–46,72], including failure to explain how treatment goals reflect patient's goals [45]. This brings to the forefront the issue of communication between therapist and patient. Several researchers have emphasized the need to improve communication and collaboration to achieve true patient-focussed goal setting [15,67,73,74]. On a positive note, recognition of this discrepancy was viewed constructively, in that goal setting might help to clarify and agree on treatment goals [38].

Although goal setting was seen as a tool to enable patient-centred care and provide motivation for the patient, several barriers were identified for this process [15,35,36,42,43,45,46], which outnumbered the motivators. The main barriers were the cognitive and communication difficulties presented by the patients, which was apparent from the number of studies that had excluded patients with these difficulties. However, as approximately a third of people with stroke present with communication and cognitive problems [75,76], a better method to involve these patients is an urgent priority.

The other barriers identified in this review were also reported frequently in studies that were excluded from this review [17,19,58,59,71,77]. Education of both patients and professionals, and improved communication, are considered to be key in overcoming these barriers [15,17,18,20,43,58,60,65,66,78]. Emphasis is placed on the importance of educating the patient on the meaning and the underlying process of goal setting, and their role in this process to enhance their participation in goal setting [17,20,43,65,66,70]. Further, education of patients on the complex nature of the disease and the recovery process could help them in setting appropriate goals [15,20,43,60]. Training professionals in goal setting methodology and communication skills, and educating them on possible patients' barriers to goal setting and successful strategies to overcome these, are also recommended [20,58,70,78,79].

Strengths and limitations

The main strength of this review is that evidence was systematically gathered from all types of studies, including those with quantitative and qualitative designs. Moreover, the review evaluated both effects and experiences of goal setting. Rigour was increased by the involvement of multiple independent reviewers at each stage. A further strength is the use of only stroke-specific data, which enables the formulation of recommendations specifically applicable to stroke rehabilitation.

A limitation of the review is that only studies published in English were included. This may have resulted in the loss of some valuable information. Moreover, the tools used for quality assessment of studies had their own limitations. Although the EPHPP form was designed for the use of non-randomized studies of various designs, some of the criteria, such as confounders, were not applicable to most of the included studies. Some of the rating criteria were not explicit (e.g. the rating for the blinding criteria) and this could have affected the overall rating of individual studies. Similarly, in the critical review form used for assessing the qualitative studies, a high degree of subjectivity was present when deciding whether or not a criterion had been met. The overall rigour of the study had only a "yes/no" answer and therefore, it was not possible to differentiate between studies with varying degrees of methodological strengths.

Conclusion

Goal setting is considered an integral part of usual stroke rehabilitation, however this review, which included 17 studies, involving 614 participants with stroke along with 43 professionals and 38 carers, brings to light the limitations of the underpinning evidence. This highlights the need for further high quality studies, especially relating to the effectiveness of goal setting. There does not appear to be one standardized method of goal setting, or consensus on how goal setting should be undertaken, especially with people with cognitive and communication problems. Discrepancy also exists between perceptions and actual practice relating to the level of patient involvement in goal setting. Therefore, more research

is required to design a patient-focussed goal setting method that could enable even those with cognitive and communication difficulties to be more actively engaged. Based on this review, recommendations for best practice include patient education on stroke recovery and goal setting, and continuing professional development for HCPs on how to increase the focus on the patient during goal setting.

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Appendix

Appendix 1. List of keywords and the combinations that were used in the Pubmed database.

	Keywords	Combination
Condition	1. "Stroke" [MeSH]	12. (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11)
	2. "Cerebrovascular disorders" [MeSH]	
	3. "Brain injury" [MeSH]	
	4. CVA$	
	5. ((Cerebrovascular OR cerebral vascular) AND (disease$ OR disorder$ OR accident$ OR trauma*))	
	6. ((Cerebral OR cerebellar or brain$ OR vertebrobasilar) AND (infarct* OR ischemi* OR thrombo* OR emboli* OR apoplexy))	
	7. ((Cerebral OR brain$ OR subarachnoid) AND (haemorrhage OR hemorrhage OR haematoma OR hematoma OR bleed*))	
	8. (Brain injur* OR brain attack OR brain damag* OR brain-damag*)	
	9. (Hemipleg* OR hemipare*)	
	10. (Post stroke OR poststroke OR post-stroke)	
	11. (Neuro* setting) OR (neuro* rehabilitation)	
Intervention	13. "Goals" [MeSH]	23. (#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22)
	14. Goal$	
	15. (Goal$ AND (set* OR plan* OR attain* OR achiev* OR assess* OR direct* OR orient*))	
	16. (goal attainment scal*)	
	17. GAS	
	18. COPM	
	19. (Canadian Occupational Performance Measure)	
	20. (Adherence AND goal$)	
	21. (Compliance AND goal$)	
	22. ((Person-centre* OR client-centre*) AND goal$)	
Condition & intervention		24. (#12 AND #23)

Appendix 4: List of keywords and the combinations that were used in the Pubmed database

	KEY WORDS	COMBINATION
CONDITION	1. "stroke" [MeSH] 2. "cerebrovascular disorders" [MeSH] 3. "brain injury" [MeSH] 4. CVA$ 5. ((cerebrovascular OR cerebral vascular) AND (disease$ OR disorder$ OR accident$ OR trauma*)) 6. ((cerebral OR cerebellar or brain$ OR vertebrobasilar) AND (infarct* OR ischaemi* OR thrombo* OR emboli* OR apoplexy)) 7. ((cerebral OR brain$ OR subarachnoid) AND (haemorrhage OR hemorrhage OR haematoma OR hematoma OR bleed*)) 8. (brain injur* OR brain attack OR brain damag* OR brain-damag*) 9. (hemipleg* OR hemipare*) 10. (post stroke OR poststroke OR post-stroke) 11. (neuro* setting) OR (neuro* rehabilitation)	12. (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11)
INTERVENTION	13. "goals" [MeSH] 14. goal$ 15. (goal$ AND (set* OR plan* OR attain* OR achiev* OR assess* OR direct* OR orient*)) 16. (goal attainment scal*) 17. GAS 18. COPM 19. (Canadian occupational performance measure)	23. (#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22)

	20. (adherence AND goal$) 21. (compliance AND goal$) 22. ((person-centre* OR client-centre*) AND goal$)	
CONDITION & INTERVENTION		24. (#12 AND #23)

Appendix 5: Table of excluded studies for the systematic review with reasons for exclusion

S.No.	Author and year	Reason for exclusion
1.	Almborg et al. (2009)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
2.	Ashford and Turner-Stokes (2006)	GAS/ COPM used only as an outcome measure
3.	Baird et al. (2000)	Qualitative paper with mixed populations
4.	Barnard et al. (2010)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
5.	Bassett and Petrie (1999)	Stroke patients not included
6.	Bergquist and Jacket (1993)	Not a clinical trial
7.	Blair (1995)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
8.	Bodiam (1999)	Response from authors that stroke specific data not available
9.	Bornman and Murphy (2006)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
10.	Bouffioulx et al. (2008)	No goal setting method used
11.	Bouwens et al. (2009)	No response from authors to provide stroke specific data
12.	Chan (1997)	Paper on psychometric properties
13.	Chen et al. (2002)	Qualitative paper with mixed populations
14.	Clare et al. (2009)	Stroke patients not included
15.	Combs et al. (2010)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
16.	Conneeley (2004)	Qualitative paper with mixed populations
17.	Cott. (2004)	Qualitative paper with mixed populations
18.	Culley and Evans (2010)	Stroke patients not included
19.	Cup et al. (2003)	Paper on psychometric properties
20.	Dedding et al. (2004)	Paper on psychometric properties
21.	Doig et al. (2009)	Stroke patients not included
22.	Doig et al. (2010)	Stroke patients not included

23.	Duff (2009)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
24.	Elsworth et al.(1999)	Not a clinical trial
25.	Eng et al. (2003)	GAS/ COPM used only as an outcome measure
26.	Ertzgaard et al. (2011)	Not a clinical trial
27.	Gagne and Hoppes (2003)	Response from authors that stroke specific data not available
28.	Gauggel and Fischer (2001)	No response from authors to provide stroke specific data
29.	Gauggel et al. (2001)	No response from authors to provide stroke specific data
30.	Gauggel et al. (2002)	No response from authors to provide stroke specific data
31.	Gauggel and Billino (2002)	No response from authors to provide stroke specific data
32.	George et al. (2001)	Full text not available in English
33.	Gordon et al. (1999)	Paper on psychometric properties
34.	Gustafsson and McLaughlin (2009)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
35.	Harris and Eng. (2004)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
36.	Haworth et al. (2009)	No goal setting method used
37.	Hermann et al. (2010)	GAS/ COPM used only as an outcome measure
38.	Hofer et al. (2010)	GAS/ COPM used only as an outcome measure
39.	Holliday et al. (2005)	Not a clinical trial
40.	Holliday et al. (2007)	No response from authors to provide stroke specific data
41.	Holliday et al. (2007)	Qualitative paper with mixed populations
42.	Hujibregts et al. (2008)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
43.	Huijbregts et al. (2009)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
44.	Jenkinson et al. (2007)	Paper on psychometric properties
45.	Joyce et al. (1994)	Paper on psychometric properties

46.	Kayes et al (2007)	Stroke patients not included
47.	Kreutzer et al. (2010)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
48.	Krueger-Brophy (1983)	Not a clinical trial
49.	Kuipers et al. (2004)	Qualitative paper with mixed populations
50.	Levack et al. (2007)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
51.	Liu et al. (2004)	No response from authors to provide stroke specific data
52.	Lohmann et al. (2011)	No goal setting method used
53.	Maitra and Erway. (2006)	No response from authors to provide stroke specific data
54.	Malec (1999)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
55.	Malec et al. (1991)	Paper on psychometric properties
56.	Malec et al. (1993)	GAS/ COPM used only as an outcome measure
57.	Mastos et al. (2007)	Stroke patients not included
58.	McClain (2005)	Not a clinical trial
59.	McCrory et al. (2009)	GAS/ COPM used only as an outcome measure
60.	McGrath and Adams (1999)	Qualitative paper with mixed populations
61.	McGrath et al. (1995)	Not a clinical trial
62.	McMillan and Sparkes (1999)	No response from authors to provide stroke specific data
63.	Monaghan et al. (2005)	No goal setting method used
64.	Morgan et al. (2002)	GAS/ COPM used only as an outcome measure
65.	Nair and Wade (2003)	Not a clinical trial
66.	Nelson and Payton (1997)	Qualitative paper with mixed populations
67.	Niemivirta (1999)	Stroke patients not included
68.	Nualnetr et al. (2010)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
69.	Olson and Irwin (2001)	Not a clinical trial
70.	Ory and Williams (1989)	Not a clinical trial

71.	Ownsworth et al. (2008)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
72.	Parry (2004)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
73.	Payton and Nelson (1996)	Qualitative paper with mixed populations
74.	Ponte-Allan and Giles (1999)	No goal setting method used
75.	Possl and Gotze (2004)	Full text not available in English
76.	Reed et al. (2010)	Did not evaluate effects of goal setting as an intervention or experiences of goal setting of patients or HCPs
77.	Rentsch and Kaufmann (2008)	Full text not available in English
78.	Rettke Geschwindner (2007)	Full text not available in English
79.	Rockwood et al. (1997)	Paper on psychometric properties
80.	Rogers (1980)	Not a clinical trial
81.	Ssl et al.(2003)	Full text not available in English
82.	Trombly et al. (1998)	Stroke patients not included
83.	Trombly et al. (2002)	Stroke patients not included
84.	Turner et al. (2009)	No goal setting method used
85.	Turner-Stokes et al. (2010)	GAS/ COPM used only as an outcome measure
86.	Turner-Stokes et al. (2009)	Paper on psychometric properties
87.	Van de Weyer et al. (2010)	Qualitative paper with mixed populations
88.	Van Vaerenbergh et al. (2006)	Not a clinical trial
89.	Wade (1999)	Not a clinical trial
90.	Wade (1999)	Not a clinical trial
91.	Wade (1999)	Not a clinical trial
92.	Wade (1999)	Not a clinical trial
93.	Wressle et al. (1999)	Paper on psychometric properties
94.	Young et al. (2008)	Qualitative paper with mixed populations
95.	Zweber and Malec (1990)	Stroke patients not included

Appendix 6: COPM data collection sheet

CODE: _____

CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

SECOND EDITION

Authors:
Mary Law, Sue Baptiste, Anne Carswell,
Mary Ann McColl, Helene Polatajko, Nancy Pollock

The Canadian Occupational Performance Measure (COPM) is an individualized measure designed for use by occupational therapists to detect self-perceived change in occupational performance problems over time.

Client Name :		
Age :	**Gender :**	**ID# :**
Respondent (if not client) :		
Date of Assessment :	**Planned date of Reassessment :**	**Date of Reassessment :**

Therapist :
Facility / Agency :
Program :

Published by CAOT Publications ACE

STEP 1:
IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES

To identify occupational performance problems, concerns and issues, interview the client, asking about daily activities in self-care, productivity and leisure. Ask clients to identify daily activities which they want to do, need to do or are expected to do by encouraging them to think about a typical day. Then ask the client to identify which of these activities are difficult for them to do now to their satisfaction. Record these activity problems in Steps 1A, 1B, or 1C.

STEP 2:
RATING
IMPORTANCE

Using the scoring card provided, ask the client to rate, on a scale of 1 to 10, the importance of each activity. Place the ratings in the corresponding boxes in Steps 1A, 1B, or 1C

STEP 1A : Self-Care

IMPORTANCE

Personal Care
(e.g., dressing, bathing, feeding, hygiene) _____ ☐
_____ ☐
_____ ☐

Functional Mobility
(e.g., transfers, indoor, outdoor) _____ ☐
_____ ☐
_____ ☐

Community Management
(e.g. transportation, shopping, finances) _____ ☐
_____ ☐
_____ ☐

1B : Productivity

Paid / Unpaid Work
(e.g. finding/keeping a job, volunteering) _____ ☐
_____ ☐
_____ ☐

Household Management
(e.g., cleaning, laundry, cooking) _____ ☐
_____ ☐
_____ ☐

Play/School
(e.g. play skills, homework) _____ ☐
_____ ☐
_____ ☐

1C : Leisure		IMPORTANCE
Quiet Recreation (e.g., hobbies, crafts, reading)	_____	☐
	_____	☐
	_____	☐
Active Recreation (e.g., sports, outings, travel)	_____	☐
	_____	☐
	_____	☐
Socialization (e.g. visiting, phone calls, parties, correspondence)	_____	☐
	_____	☐
	_____	☐

STEPS 3 & 4: SCORING - INITIAL ASSESSMENT and REASSESSMENT

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

Initial Assessment:			**Reassessment:**	
OCCUPATIONAL PERFORMANCE PROBLEMS:	**PERFORMANCE 1**	**SATISFACTION 1**	**PERFORMANCE 2**	**SATISFACTION 2**
1. _____	☐	☐	☐	☐
2. _____	☐	☐	☐	☐
3. _____	☐	☐	☐	☐
4. _____	☐	☐	☐	☐
5. _____	☐	☐	☐	☐
SCORING:	**PERFORMANCE SCORE 1**	**SATISFACTION SCORE 1**	**PERFORMANCE SCORE 2**	**SATISFACTION SCORE 2**
Total Score = Total performance or satisfaction scores / # of problems	/ = ☐	/ = ☐	/ = ☐	/ = ☐

CHANGE IN PERFORMANCE = Performance Score 2 ☐ - Performance Score 1 ☐ = ☐

CHANGE IN SATISFACTION = Satisfaction Score 2 ☐ - Satisfaction Score 1 ☐ = ☐

ADDITIONAL NOTES AND BACKGROUND INFORMATION:

Initial Assessment

Reassessment

Appendix 7: Goal setting workbook

1. What is goal setting?

Goal setting is the process by which you identify your problems and set specific goals to overcome the problems and achieve something that you want to achieve.

2. How will goal setting work?

Working towards your own goals can help you stay focussed; improve your confidence; give you a sense of achievement and make you want to do more.

3. What type of goals should I set?

As you will be going to the exercise classes, it would be helpful to set goals related to the exercises you do.

4. Will I get help to set my goals?

We will discuss your problems with you and help you to choose a long term goal that you would like to achieve. We will also help you in deciding your weekly goals until you can do it by yourself.

5. How should I use this work book?

You can write your monthly and weekly goals in this book. You can also note down your progress. You can add your comments on how you work towards your goals.

6. How will this work book help me?

Writing your goals in this workbook can help you remember the goals. You can also see if you are moving closer to your goal.

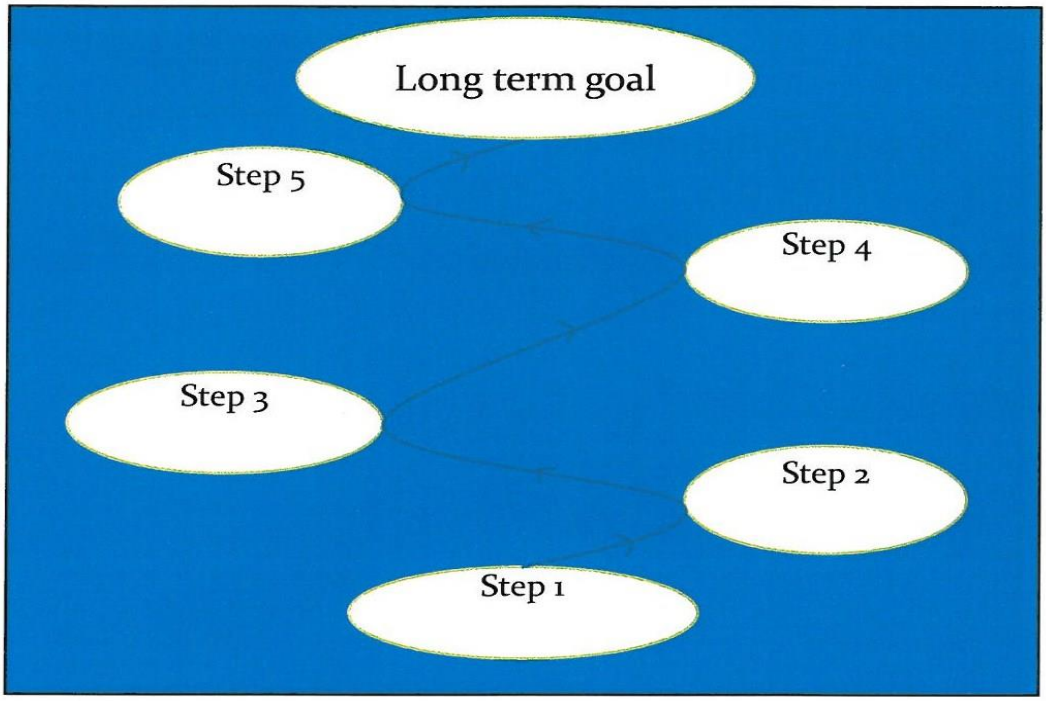
Go for Your GOAL

My long term goals are

1.

2.

3.



Month 1

My goals for the next 4 to 5 weeks are:

1.

2.

3.

Week 1

My goals for this week are:

1.

2.

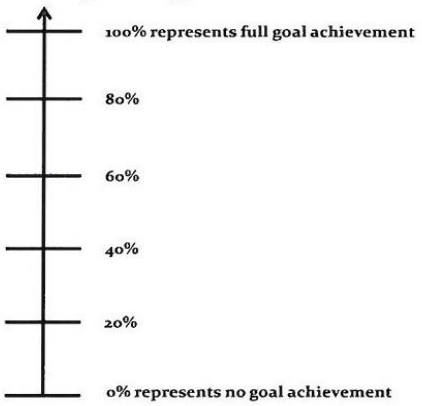
3.

Week 1

	Did you remember your goals today?	Did you work towards your goals today?	Comments
Monday	Yes / No	Yes / No	----------
Tuesday	Yes / No	Yes / No	----------
Wednesday	Yes / No	Yes / No	----------
Thursday	Yes / No	Yes / No	----------
Friday	Yes / No	Yes / No	----------
Saturday	Yes / No	Yes / No	----------
Sunday	Yes / No	Yes / No	----------

Week 1

At the end of the week, make a note on how you have done on working towards your goals



Questions to contemplate

1. What is helping you move towards your goals?
2. What is hindering your progress on moving towards your goals?
3. What do you do to overcome these difficulties?
4. How does working towards your goals make you feel?
5. Any other comments.

Week 2

My goals for this week are:

1.

2.

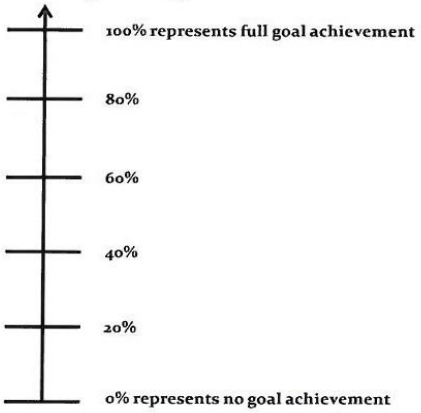
3.

Week 2

	Did you remember your goals today?	Did you work towards your goals today?	Comments
Monday	Yes / No	Yes / No	----------
Tuesday	Yes / No	Yes / No	----------
Wednesday	Yes / No	Yes / No	----------
Thursday	Yes / No	Yes / No	----------
Friday	Yes / No	Yes / No	----------
Saturday	Yes / No	Yes / No	----------
Sunday	Yes / No	Yes / No	----------

Week 2

At the end of the week, make a note on how you have done on working towards your goals



Questions to contemplate

1. What is helping you move towards your goals?
2. What is hindering your progress on moving towards your goals?
3. What do you do to overcome these difficulties?
4. How does working towards your goals make you feel?
5. Any other comments.

Week 3

My goals for this week are:

1.

2.

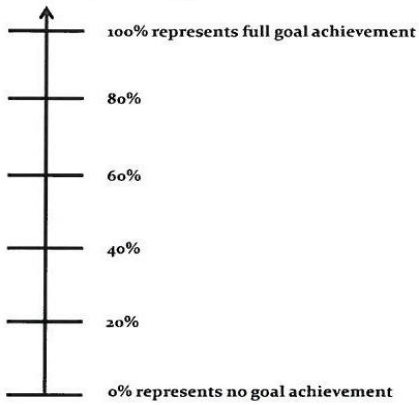
3.

Week 3

	Did you remember your goals today?	Did you work towards your goals today?	Any comments?
Monday	Yes / No	Yes / No	----------
Tuesday	Yes / No	Yes / No	----------
Wednesday	Yes / No	Yes / No	----------
Thursday	Yes / No	Yes / No	----------
Friday	Yes / No	Yes / No	----------
Saturday	Yes / No	Yes / No	----------
Sunday	Yes / No	Yes / No	----------

Week 3

At the end of the week, make a note on how you have done on working towards your goals



Questions to contemplate

1. What is helping you move towards your goals?
2. What is hindering your progress on moving towards your goals?
3. What do you do to overcome these difficulties?
4. How does working towards your goals make you feel?
5. Any other comments.

Week 4

My goals for this week are:

1.

2.

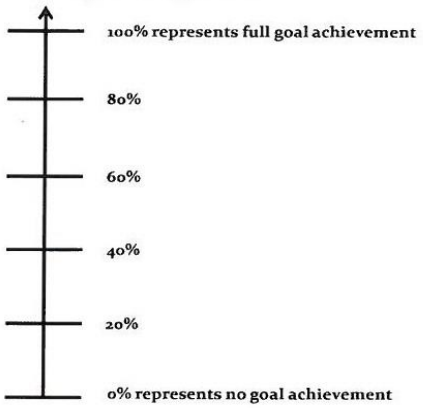
3.

Week 4

	Did you remember your goals today?	Did you work towards your goals today?	Any comments?
Monday	Yes / No	Yes / No	----------
Tuesday	Yes / No	Yes / No	----------
Wednesday	Yes / No	Yes / No	----------
Thursday	Yes / No	Yes / No	----------
Friday	Yes / No	Yes / No	----------
Saturday	Yes / No	Yes / No	----------
Sunday	Yes / No	Yes / No	----------

Week 4

At the end of the week, make a note on how you have done on working towards your goals



Questions to contemplate

1. What is helping you move towards your goals?
2. What is hindering your progress on moving towards your goals?
3. What do you do to overcome these difficulties?
4. How does working towards your goals make you feel?
5. Any other comments.

Week 5

My goals for this week are:

1.

2.

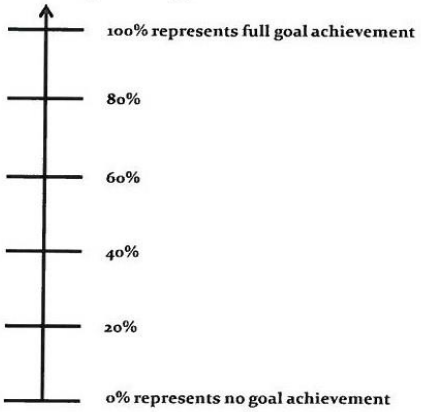
3.

Week 5

	Did you remember your goals today?	Did you work towards your goals today?	Any comments?
Monday	Yes / No	Yes / No	----------
Tuesday	Yes / No	Yes / No	----------
Wednesday	Yes / No	Yes / No	----------
Thursday	Yes / No	Yes / No	----------
Friday	Yes / No	Yes / No	----------
Saturday	Yes / No	Yes / No	----------
Sunday	Yes / No	Yes / No	----------

Week 5

At the end of the week, make a note on how you have done on working towards your goals

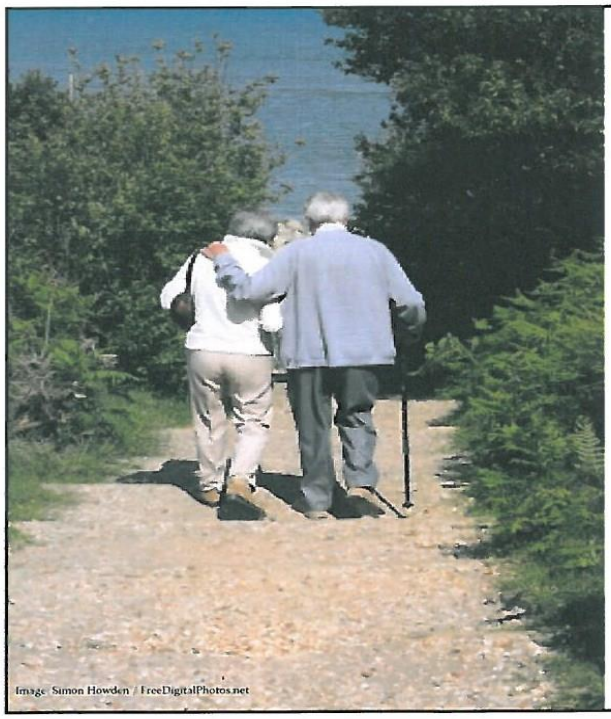


Questions to contemplate

1. What is helping you move towards your goals?
2. What is hindering your progress on moving towards your goals?
3. What do you do to overcome these difficulties?
4. How does working towards your goals make you feel?
5. Any other comments.

At the end of the month

On looking back at the goals you set in the beginning, what do you feel you have achieved / not achieved?



Hope you enjoyed working towards your goals and completing this workbook!

You will be given a new workbook for the next month.
See you soon!

Appendix 8: Ethical approval documents for study three

Research Ethics Committee approval letter

Lothian NHS Board

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9009
www.nhslothian.scot.nhs.uk

NHS
Lothian

South East Scotland Research Ethics Committee 03
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS

Telephone: 0131 536 9022
Facsimile: 0131 536 9346

23 October 2009

Mrs Thavapriya ShanmugaSundaram
PhD student
Queen Margaret University
PhD student
Physiotherapy subject area,
Queen Margaret University,Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

Study Title: **An investigation of the effects and experiences of goal setting for exercise after stroke - A feasibility study.**
REC reference number: **09/S1103/35**
Protocol number: **V.1.**

Thank you for your letter of 13 October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the chair on behalf of SESREC 3.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only: management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		20 August 2009
REC application	V2.2	20 August 2009
Investigator CV		20 August 2009
Participant Information Sheet: Instruction sheet for the Activity Monitor		13 August 2009
Evidence of insurance or indemnity		03 August 2009
Letter from Sponsor		Oct 2009
Questionnaire: THE STOKE SELF-EFFICACY QUESTIONNAIRE	V.1	
Stroke Impact Scale	V. 3	
Ten Metre Walk Test		
Timed Up & Go (TUG) Test		
Letter from Sponsor		20 August 2009
Letter from Statistician	1	19 August 2009
Further cover letter info		20 August 2009
Protocol	2	13 October 2009
Response to Request for Further Information		13 October 2009
Participant Information Sheet: PIS Study 1 Pilot	2	13 October 2009
GP/Consultant Information Sheets	2	13 October 2009
Letter of invitation to participant	2 pilot	16 October 2009
Participant Consent Form: PCF	2	13 October 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S1103/35	**Please quote this number on all correspondence**

Yours sincerely

Dr Christine West
Chair

Email: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures:

"After ethical review – guidance for researchers" *[SL-AR1 for CTIMPs, SL- AR2 for other studies]*

Copy to: *Professor Marie Donaghy*
[R&D office for NHS care organisation at lead site]

Research and Development approval letter

NHS
Lothian

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

Research & Development
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email:
R&DOffice@luht.scot.nhs.uk

Director:
Professor David E Newby

DEN/JB/approval

29 October 2009

Mrs Thavapriya ShanmugaSundaram
Physiotherapy subject area
Queen Margaret University
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram,

Lothian R&D Project No: **2009/R/UO/13**

Title of Research: An investigation of the effects and experiences of goal setting for exercise after stroke- A Pilot study.

MREC No: N/A

LREC No: 09/S1103/35

CTA No: N/A

Eudract: N/A

PIS: Version 2 dated October 2009

Consent: Version 2 dated October 2009

Protocol No: Version 2 dated October 2009

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the project such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

Professor David E Newby
R&D Director

enc Research Governance Certificate ✓(to be signed and returned)

Research Ethics Committee amendment one approval letter

Lothian NHS Board

South East Scotland Research
Ethics Committee 03
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 536 9088

www.nhslothian.scot.nhs.uk
Date
Our Ref
Enquiries to Joyce Clearie
Extension 35674
Direct Line 0131 465 5674
Email joyce.clearie@nhslothian.scot.nhs.uk

07 June 2011

Mrs Thavapriya ShanmugaSundaram
PhD student
Queen Margaret University
Physiotherapy subject area,
Queen Margaret University, Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

Study title: **An investigation of the effects and experiences of goal setting for exercise after stroke - A feasibility study.**
REC reference: **09/S1103/35**
Protocol number: **N/A**
Amendment number:
Amendment date: **02 June 2011**

Thank you for the above amendment .The amendment is valid and was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form	3	02 June 2011
Participant Information Sheet	3	02 June 2011

Protocol	3	02 June 2011
Notice of Substantial Amendment (non-CTIMPs)		02 June 2011

Membership of the Committee

The members of the Committee who took part in the review are listed below
Dr C West and Mr W Taylor

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S1103/35: **Please quote this number on all correspondence**

Yours sincerely

Dr Christine West
Chair

E-mail: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures. *List of names and professions of members who took part in the review*

Copy to: *Professor Marie Donaghy*
Dr Tina McLelland, R&D NHS Lothian

Research Ethics Committee amendment two approval letter

Lothian NHS Board

South East Scotland Research
Ethics Committee 03
Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000
Fax 0131 536 9088

www.nhslothian.scot.nhs.uk
Date
Our Ref
Enquiries to Joyce Clearie
Extension 35674
Direct Line 0131 465 5674
Email joyce.clearie@nhslothian.scot.nhs.uk

08 March 2012

Mrs Thavapriya ShanmugaSundara
PhD student
Physiotherapy subject area,
Queen Margaret University,
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

Study title:	**An investigation of the effects and experiences of goal setting for exercise after stroke - A feasibility study.**
REC reference:	**09/S1103/35**
Protocol number:	**N/A**
Amendment number:	
Amendment date:	**06 March 2012**

Thank you for submitting the above amendment, which was received on 07 March 2012. I can confirm that this is a valid notice of a substantial amendment. The amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	4	06 March 2012
Notice of Substantial Amendment (non-CTIMPs)		06 March 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

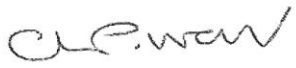
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S1103/35:	**Please quote this number on all correspondence**

Yours sincerely



Dr Christine West
Chair

E-mail: joyce.clearie@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Research and Development amendment approval letter

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

NHS Lothian

RESEARCH & DEVELOPMENT
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email: R&DOffice@luht.scot.nhs.uk

Director: Professor David E Newby

KM/JK

19 March 2012

Mrs Thavapriya ShanmugaSundaram
Physiotherapy Subject Area
Queen Margaret University
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

REC No:	09/S1103/35
R&D Project ID No:	2009/R/UO/13
Amendment:	Substantial amendment No.2 dated 6 March 2012
Title of Research	An investigation of the effects and experiences of goal setting for exercise after stroke- A Pilot study.

I am writing in reply to recent correspondence in relation to an amendment(s) to the above project and the subsequent updated documents as follows.

- Protocol, version 4 dated March 2012

We have now assessed any consequential changes and can confirm that NHS Lothian management approval is extended to cover the specific changes intimated.

Yours sincerely

Ms Karen Maitland
Research Governance Coordinator

Appendix 9: Participant information sheet and consent form for study three

Queen Margaret University
EDINBURGH

LETTER OF INVITATION

Date:

We would like to invite you to take part in the pilot study of the following research project.

Study Title:
Effects and experiences of goal setting for exercise after stroke – A pilot study.

Before you decide, you need to understand why the research is being done and what it would involve for you. Therefore, we have attached a detailed information sheet for you.

If you are willing to participate or would like to ask us any further questions regarding the study, please contact us with the contact details provided in the information sheet.

Thank you for your consideration.

With kind regards,

Thavapriya ShanmugaSundaram

Queen Margaret University
EDINBURGH

PARTICIPANT INFORMATION SHEET

Study Title:
Effects and experiences of goal setting for exercise after stroke – A pilot study.

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study

If you have any questions, you can talk to us. Take your time to decide whether or not you wish to take part.

PART I

What is the purpose of the Study?

During usual stroke rehabilitation, a process called 'Person-centred goal setting' is used to help the person affected by the stroke to identify and agree goals e.g. walking without a stick. Although goal setting in used in stroke rehabilitation units, it has not been used in people during exercise training after stroke. So, we have designed a goal setting program that can be used for exercise training after stroke. Now, we would like to conduct a small pilot study to fine-tune the goal setting program and to standardise the assessment procedures.

Do I have to take part?

It is entirely up to you to decide. You can take up to 7 days to make your decision. If you decide to take part, we will then ask you to sign a consent form. You are free to withdraw from this study at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

You will be involved in this study for 2 weeks. You will have two visits in this period, one to two weeks apart. Each visit should take no longer than two hours. The study will

be conducted at the Gait Laboratory of Queen Margaret University, Edinburgh. For the study, you will be asked to wear shorts (so that we can attach the monitor on the thighs); also wear the splints you normally use; and bring with you any walking aid that you use.

At each visit, we will go through the following assessments:
a) Performing simple tests with two activity monitors attached:
The Activity monitor is a small piece of equipment that will record your activity (sitting/lying, standing and stepping). To check the accuracy of the activity monitor, we will need two monitors to compare the recorded activity. Therefore, we will attach two small physical activity monitor to your thighs (one on each thigh) with sticky pads (see figure 1). The monitors are very small (size of a matchbox) and lightweight (20gms). In sitting, we will ask you to fill two questionnaires on your daily activities, mobility, memory, communication, quality of life and confidence. Then, we will ask you to walk for 10 metres, or if you can't walk for this long, we will ask you to walk as far as you can. If you are able and willing to, we will also ask you to climb a small flight of stairs.

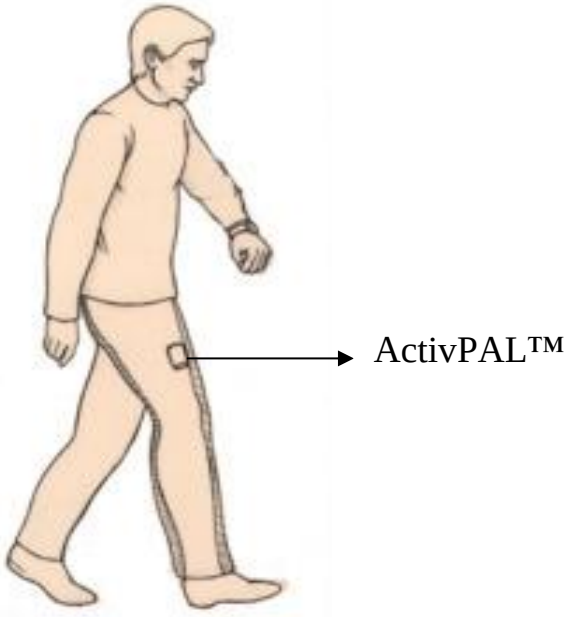


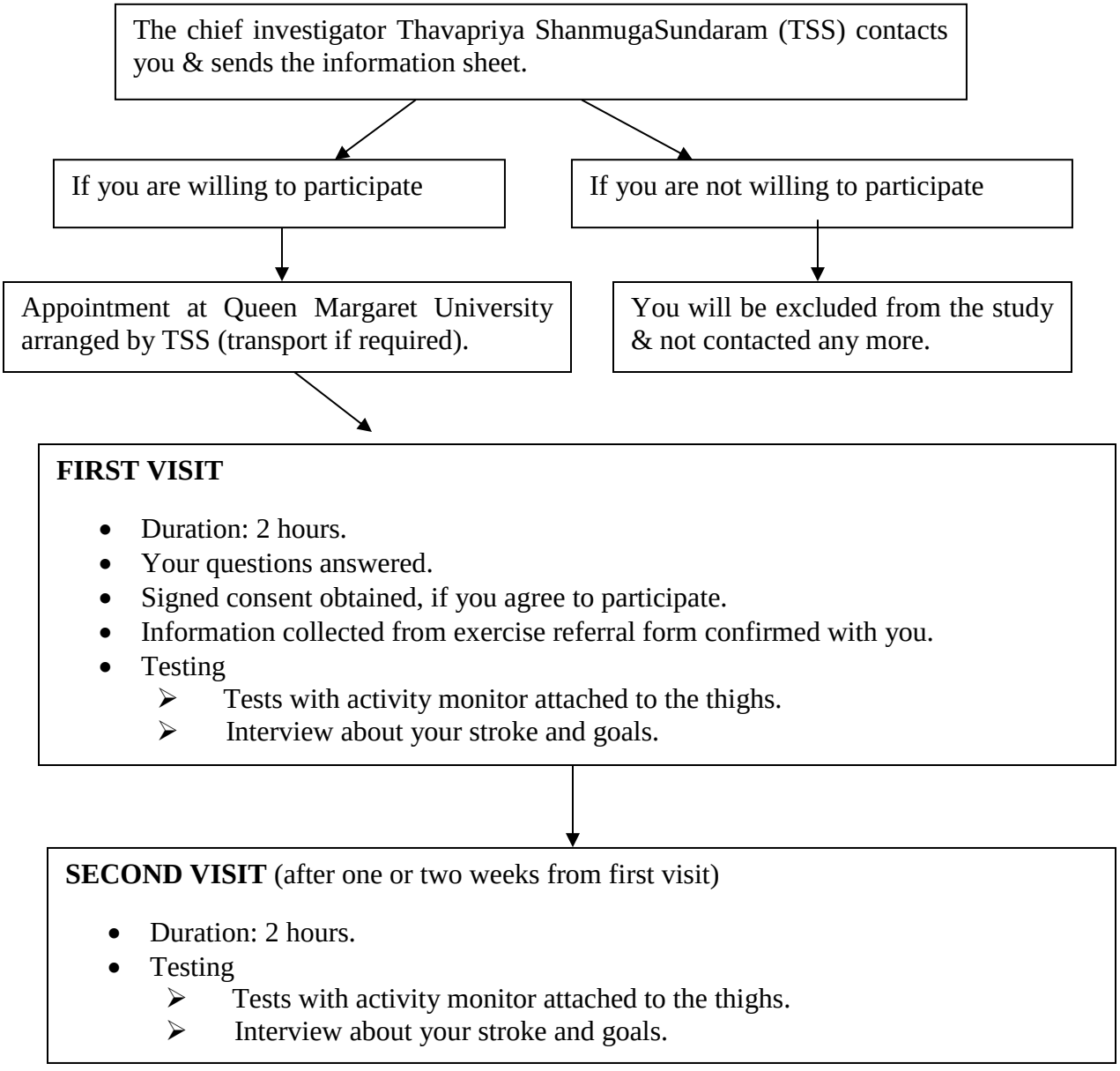
Figure 1. A person walking with an activPAL™ attached to the thigh.
(Source: http://www.paltech.plus.com/products.htm)

We will make every effort to minimise the risk of a stumble or fall. You may feel a little tired afterwards but the tests should not cause any pain or discomfort. We will give you adequate rest in between to make sure you do not get tired.

b) We will interview you:
In one of the visits, we will ask you about your goals in the form of an interview. In the other visit, we will ask you about your stroke and how the stroke has affected you. The order will be decided by chance. If you agree, the interviews will be audio taped for quality assurance.

If you agree, the whole procedure will be video taped to compare the recorded activity from the activity monitor with the video tapes. We will remove the monitors once the procedure is completed.

The whole procedure is outlined as a chart below:



You can bring a relative or friend or carer with you.

Expenses
Travel expenses to and from Queen Margaret University for you and for any person who accompanies you (carer, friend or relative) will be paid back to you.

What are the possible disadvantages and risks of taking part?
The study procedure is generally safe. Any minimal risk such as the possibility to fall, trip etc. has been minimised by undertaking a comprehensive risk assessment of the procedure and the site.

What are the possible benefits of taking part?
There may not be any direct benefit to you by taking part in this study but you will be helping in improving the procedures for goal setting. This will allow us to conduct the next study which involves clients who are new to the Exercise after Stroke service. The information we get from this project will help in identifying if formal goal setting methods are beneficial in the area of exercise after stroke. If effective, it could be introduced as part of the exercise service in the future.

Will my health and safety be taken care of?
In terms of your health and safety, a comprehensive risk assessment for all the study procedures will be undertaken, using the guidelines set out by Queen Margaret University. Any potential safety issues will be dealt with prior to your visit. During your visit, our standard health, safety and emergency procedures will be applied as and when required.

What if there is a problem?
Any complaint about the study, the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information on this is given in part 2 of the information sheet.

Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in part 2 of the information sheet.

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering in taking part, please continue to read the additional information in Part 2 before making any decision.

PART 2

What will happen if I don't want to carry on with the study?

You are free to withdraw from this study at any time, without giving a reason. If you agree, the data collected previously will be used. If not, all previously collected data will be destroyed.

What if there is a problem?

Any complaint about the study, the way you have been dealt with during the study or any possible harm you might suffer due to negligence will be addressed. Queen Margaret University has a liability insurance scheme for compensation as a result of harm caused due to the negligence on the part of the researcher in connection with the above mentioned study but there are no compensation arrangements for non negligent harm.

Will my taking part in the study be kept Confidential?

Once you have signed the consent form, a study participation number will be assigned to you and this number will be used throughout the research to maintain your confidentiality. All personal information collected will be kept strictly confidential. The data, audio tapes used during the interviews and video tapes will be stored securely in locked cabinets in Queen Margaret University and only the research team will have access to it. Care will be taken through removing the names and addresses on any information presented, published or taken out of the premises for any reason.

Extracts from the interview may be used in the thesis and in any published material. However, no personal information will be revealed in any of this.

The data will be accessed only by researchers involved in the study and the research committee responsible for monitoring the quality of research. All the data collected will be kept for 5 years and will be then disposed of carefully.

The usual procedures for confidentiality, health and safety, and other research governance procedures operated by Queen Margaret University will be applied to this study. More details on QMU's research governance can be found on the following website: http://www.qmu.ac.uk/research_knowledge/ethics.htm.

Involvement of the General Practitioner/Family doctor (GP)

If you agree, your General Practitioner will be informed in writing about your participation in the study. If needed and only if you agree, we may also contact your GP to obtain further information on your medical condition.

What will happen to the results of the research study?

The results of the study will be published on the form of a thesis at Queen Margaret University as well as research papers in scientific journals and conferences. Care will be taken that the participants are not identifiable in any of the materials published.

Who is organising and funding the Research?
Queen Margaret University funds this study as a PhD degree. The study is conducted by Thavapriya ShanmugaSundaram, a research student of Queen Margaret University, Edinburgh.

Who has reviewed the study?
This study was given a favourable ethical opinion by the Lothian Research Ethical Committee.

Thank you for your time. If you have any questions, please contact Mrs. Thavapriya ShanmugaSundaram during office hours.

Contact Details:

Thavapriya ShanmugaSundaram
Research Student
Physiotherapy Subject Area
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 07989184486, 01314740000
E-mail: tshanmugasundaram@qmu.ac.uk

Dr. Cathy Bulley
Senior Lecturer
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: cbulley@qmu.ac.uk

If you would like to talk to an independent person who is not directly involved in the study, but who knows about the study, please contact Dr. Marietta van der Linden during office hours.

Independent Contact:

Dr. Marietta van der Linden
Research Fellow Physiotherapy
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: mvanderlinden@qmu.ac.uk

Please note: For telephone contacts, Queen Margaret University has a voice operated system in use. So when telephoning, please speak to an operator who will connect you through to the person requested.

Queen Margaret University
EDINBURGH

Participant's Identification number: Study number:

CONSENT FORM

Title of the Project: "Effects and experiences of goal setting for exercise after stroke – A pilot study".

Name and address of the Researcher:
Thavapriya ShanmugaSundaram
Research Student, Physiotherapy Subject Area,
Queen Margaret University
Edinburgh EH21 6UU
Tel: 0131 474 0000
E-mail: tshanmugasundaram@qmu.ac.uk

Please initial box

I confirm that I have read and understood the information sheet (version 3, study 1, June 2011). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that I am under no obligation to take part in this study. ☐

I understand that I have the right to withdraw from this study at any stage without giving any reason. ☐

I understand that audio tapes will be used during the study and I agree to my being audiotaped in this study. ☐

I understand that video tapes will be used during the study and I agree to my being videotaped in this study. ☐

I understand that all information collected will be used only for research purposes and that I will not be identified from it. ☐

I agree to my GP being informed of my participation in the study. ☐

I agree to my GP being asked for more information on my medical condition. ☐

I agree to take part in this study. ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

When completed, one copy for participant and one copy for researcher site file.

Appendix 10: Pre-pilot work of study three

Since the study three had multiple aims, several components were involved and therefore, pre-pilot work was done to finalise the study procedure. Two healthy female students volunteered to be participants for this work. Initially, the study was designed to be conducted at different stations (i.e. one area for the 10MWT, one area for completing questionnaires and so on) within the same room. It was also planned to start and stop the activPAL™ at the beginning and the end of each activity/test using an activPAL™ key. When data was collected by this method, it was found that there was a possibility that the activPAL™ may not switch on/off correctly leading to incorrect data recording. Moreover, the activities were of short duration and previous studies in healthy populations had used the monitor for durations longer than 30 minutes (Grant et al. 2006, Ryan et al. 2006). In line with this, it was decided not to stop the activPAL™ between tests and let it run for the entire duration of the study session.

Accommodating this change raised another issue. Since the activPAL™ was not stopped in between tests, it required the video camera to be recording continuously. However, the size of the room made it difficult to place the video camera in a position so that it would be able to capture all the movements. Having two cameras in different positions did not resolve the issue as not all movements could be recorded and the cut-off points between the two video cameras could not be defined accurately. Therefore, it was decided to conduct the activities within the focus of one video camera. This was achieved by placing the video camera on the floor behind the chair in which the participant sat. The video camera was adjusted so that it focused on the participant's leg while sitting and while the participant was walking, it was able to capture the walking motion of the lower limbs. All the activities were performed within this straight line of focus by moving the required equipment rather than the participant moving between stations (e.g. for the participants to complete the questionnaires, the participants remained sitting in the chair, while the researcher moved a table close to the participant instead of the participant having to move towards a table).

Since the activPAL™ operates in epochs of 15 seconds, it was decided to incorporate a 20 second time period in between transitions. However, this could not be done for the TUG test as the test is a measure of time required to complete one continuous bout of activity.

The manufacturers recommend that the activPAL™ to be placed on the mid-line of the thigh, about a third of the way down between the hip to the knee (PAL Technologies Ltd 2010). For consistency and accuracy, a standard procedure of measurement was followed to determine the placement position of the activPAL™ for all participants. In standing, the length of the anterior aspect of the thigh between the anterior superior iliac spine and upper border of patella was measured and one third of this distance was calculated. The activPAL™ was positioned at this point.

While observing the video recordings, it became apparent that feet shuffling and dragging could be mistaken for a step. Therefore, it was decided to define a 'step' for consistency and accuracy. What constitutes a step was not explained in the activPAL™ manual (PAL Technologies Ltd 2010), and hence other sources were considered. Every heel-strike or every toe-off could be counted as a step. However, within stroke populations, the gait pattern could differ (no heel strike, no toe-off), and the calculation of step count could be difficult. Therefore, the definition used by McAloon (2007) was chosen. Accordingly, a step is defined as, "the point of initial contact of the foot where mass is transferred to the next consecutive point of contact of that foot where mass is transferred (the consecutive point of contact of the foot does not necessarily have to be the same part of the foot)" (McAloon 2007, p.31). During shuffling or feet dragging, there would be no transference of mass between the feet and hence, this was not counted as a step.

Appendix 11: Ethical approval documents for study four

Research Ethics Committee approval letter

South East Scotland Research Ethics Committee 01
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

Telephone:
Facsimile:

03 November 2011

Mrs Thavapriya ShanmugaSundaram
Queen Margaret University
Physiotherapy subject area,
Queen Margaret University,Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram,

Study title: **Effects and experiences of goal setting for exercise after stroke - A feasibility study**
REC reference: **11/SS/0062**

The Research Ethics Committee reviewed the above application at the meeting held on 02 November 2011. Thank you for attending to discuss the study.

Ethical opinion
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites
NHS Sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non NHS sites
Notification(s) of no objection have been received from local assessors for the non-NHS site(s) listed in the table below, following site-specific assessment (SSA).

I am pleased to confirm that the favourable opinion applies to the following research site(s), subject to site management permission being obtained prior to the start of the study at the site (see under 'Conditions of the favourable opinion below').

Research Site	Principal Investigator / Local Collaborator
Gait Laboratory of Queen Margaret University	Mrs Thavapriya ShanmugaSundaram

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.
Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other conditions specified by the REC

The participant information sheet should:
1. explain what was current treatment and what was research related
2. mention that feedback would be available, and explain how participants could obtain a copy
3. mention that if participants withdraw or lose capacity, the data collected would be retained subject to their agreement
4. delete one of the references to 'confidentiality' on page 8
5. delete the reference to the Ethics Committee having access to the data (page 9)
6. correct the name of the ethics committee who approved the application i.e. South East Scotland Ethics Committee 01 (page 10) 2.

The consent form should seek:
1. specific consent for the 'goals to be sent to Edinburgh Leisure
2. specific consent to retain data collected up to the point the participant withdraws or loses capacity.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents
The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
GP/Consultant Information Sheets	1	30 September 2011
Investigator CV		
Letter of invitation to participant	1	30 September 2011
Other: Goal Setting Workbook	1	30 September 2011
Other: Canadian Occupational Performance Measure		
Other: Activpal Instruction Sheet	1	30 September 2011
Participant Consent Form	1	30 September 2011
Participant Information Sheet	1	30 September 2011
Protocol	1	30 September 2011

Questionnaire: SIS		
Questionnaire: SSEQ		
REC application		18 October 2011
Summary/Synopsis	1	30 September 2011

Membership of the Committee
The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

11/SS/0062 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Janet Andrews
Chair

Email: alex.bailey@lhb.scot.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

Research and Development approval letter

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

NHS Lothian

Research & Development
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343

Email:

R&DOffice@luht.scot.nhs.uk

Director:

Professor David E Newby

CPP/SS/approval

03 November 2011

Mrs Thavapriya ShanmugaSundaram
Physiotherapy subject area
Queen Margaret University
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram,

Lothian R&D Project No: **2011/P/PT/02**

Title of Research: Effects and experiences of goal setting for exercise after stroke - a feasibility study

REC No: 11/SS/0062

CTA No: N/A **Eudract:** N/A

PIS: Version 1, Study 2 Dated September 2011 **Consent:** Version 1, Study 2, Dated September 2011

Protocol No: Version 1 Dated September 2011

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Following a Research Ethics Committee final favourable opinion, final copies of all project documentation (with revised version numbers) should be sent, with the Research Ethics Committee letter of favourable opinion, to the R&D office. Management approval will only be valid after favourable opinion has been received.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

CPhillips

Dr Christine P Phillips
Deputy R&D Director

Cc Paul Dearie, QA Manager

Research Ethics Committee documents approval letter

South East Scotland Research Ethics Committee 01

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk

NHS Lothian

Mrs Thavapriya ShanmugaSundaram
PhD student
Queen Margaret University
PhD student
Physiotherapy subject area,
Queen Margaret University,Edinburgh
EH21 6UU

Date: 9 November 2011
Your Ref.:
Our Ref.: 11/SS/0062

Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Mrs ShanmugaSundaram

Full title of study: **Effects and experiences of goal setting for exercise after stroke - A feasibility study**

REC reference number: **11/SS/0062**

Thank you for sending the documents listed below as evidence of compliance with the approval conditions detailed in the Committee's letter of letter 2 November 2011. Please note these documents are for information only and have not been reviewed by the Committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Consent Form	2: Study 2	09 November 2011
Participant Information Sheet	2: Study 2	09 November 2011

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/SS/0062 **Please quote this number on all correspondence**

Yours sincerely

WALTER HUNTER
Committee Coordinator

Research and Development documents approval letter

University Hospitals Division

NHS Lothian

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

RESEARCH & DEVELOPMENT
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email: R&DOffice@luht.scot.nhs.uk

Director: Professor David E Newby

KM/JK/app-mrecamend

12 December 2011

Mrs Thavapriya ShanmugaSundaram
PhD Student
Physiotherapy subject area
Queen Margaret University
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

REC No: **11/SS/0062**
R&D Project ID No: **2011/P/PT/02**
Title of Research *Effects and experiences of goal setting for exercise after stroke - a feasibility study*

I am writing in reply to recent correspondence in relation to the following amendment(s) to the above project.

Minor Amendment: **Dated November 2011**

- **Minor changes to study documentation as requested by South East Scotland Research Ethics Committee.**
  - **Participant information sheet: Study 2, version 2 dated November 2011**
  - **Letter of invitation: Study 2, version 2 dated November 2011**
  - **Consent form: Study 2, version 2 dated November 2011**

We have now received a copy of the amendment(s) and assessed any consequential changes in NHS Lothian resource use. I confirm that NHS Lothian management approval is extended to cover the specific changes intimated.

Yours sincerely

Ms Karen Maitland
Research Governance Co-ordinator

Research Ethics Committee amendment one approval letter

South East Scotland Research Ethics Committee 01
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG

Tel: 0131 465 5679

21 March 2012

Mrs Thavapriya ShanmugaSundaram
PhD student
Queen Margaret University
PhD student
Physiotherapy subject area,
Queen Margaret University,
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram

Study title:	**Effects and experiences of goal setting for exercise after stroke - A feasibility study**
REC reference:	**11/SS/0062**
Amendment number:	**01**
Amendment date:	**15 March 2012**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)		15 March 2012
Participant Consent Form	Version 3, study 2	15 March 2012
Participant Information Sheet	Version 3, study 2	15 March 2012
Protocol	Version 2	15 March 2012
Letter of invitation to participant	Version 3, study 2	15 March 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/SS/0062:	Please quote this number on all correspondence

Yours sincerely

Dr Janet Andrews
Chair

E-mail: Sandra.Wyllie@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *N/A. R&D contact not specified in database.*
Dr Fiona Coutts

Research and Development amendment one approval letter

University Hospitals Division

NHS Lothian

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

RESEARCH & DEVELOPMENT
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email:
R&DOffice@luht.scot.nhs.uk

Director:
Professor David E Newby

KM/SS

21 March 2012

Mrs Thavapriya ShanmugaSundaram
PhD Student
Physiotherapy Subject Area
Queen Margaret University
Edinburgh
EH21 6UU

Dear Mrs ShanmugaSundaram,

REC No:	11/SS/0062
R&D Project ID No:	2011/P/PT/02
Amendment:	Substantial amendment No.1 dated March 2012
Title of Research:	Effects and experiences of goal setting for exercise after stroke - a feasibility study

I am writing in reply to recent correspondence in relation to an amendment(s) to the above project and the subsequent updated documents as follows.

- Protocol Version 2 dated March 2012
- Consent Form Version 3, study 2 dated March 2012
- Letter of Invitation and Patient Information Sheet Version 3, study 2 dated March 2012

We have now assessed any consequential changes and can confirm that NHS Lothian management approval is extended to cover the specific changes intimated.

Yours sincerely

Ms Karen Maitland
Research Governance Coordinator

"Improving health through excellence and innovation in clinical research"

Appendix 12: Participant information sheet and consent form for study four

Queen Margaret University
EDINBURGH

LETTER OF INVITATION

Date:

We would like to invite you to take part in the main study (study 2) of the following research project.

Study Title:
Effects and experiences of goal setting for exercise after stroke.

Before you decide you need to understand why the research is being done and what it would involve for you. Therefore, we have attached a detailed information sheet for you.

If you are willing to participate or would like to ask us any further questions regarding the study, please contact us with the contact details provided in the information sheet.

Thank you for your consideration.

With kind regards,
Thavapriya ShanmugaSundaram

Queen Margaret University
EDINBURGH

PARTICIPANT INFORMATION SHEET FOR STUDY 2

Study Title:
Effects and experiences of goal setting for exercise after stroke.

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of the study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study

If you have any questions, you can talk to us. Take your time to decide whether or not you wish to take part.

PART I

What is the purpose of the Study?

Exercise training is recommended for people affected by stroke, but improvements gained can be lost after some time. During usual stroke rehabilitation, a process called 'goal setting' is used to help the person affected by the stroke to identify and agree goals for their recovery, e.g. walking without a stick. This is considered best practice and done to ensure that the rehabilitation programme meets the needs of each individual. Although goal setting is used in stroke rehabilitation units, it has not been used in people during exercise training after stroke. We are interested in the kinds of goals people set in the context of exercise after stroke, and are looking at ways in which the exercise service might be improved. So, we have designed a goal setting program that can be used for exercise training after stroke. Now, we want to find out the effects of the program on physical activity, confidence and quality of life. We also want to find out what the people think about the goal setting program.

Why have I been invited?

All the new clients who are referred to the exercise after stroke sessions run by … are being invited to take part in this study. As you are referred to this class, you are also being invited.

Do I have to take part?

It is entirely up to you to decide. You can take up to 7 days to make your decision. If you decide to take part, we will then ask you to sign a consent form. You are free to

withdraw from this study at any time, without giving a reason. This would not affect the standard of care you receive.

Will any part of my regular exercise program be changed if I take part in the study?
No. Exercise instructors at … undertake some goal setting as part of usual practice. If you take part in the study, goal setting will be done in more depth and detail through personal interview. This is explained in detail in the next section.

What will happen to me if I take part?
For this study, you will have 5 visits spread out over a total of 16 weeks. You will have 2 visits before you begin your exercise classes (4 weeks apart), then at 4 weeks, 8 weeks, and 12 weeks, from the time you start your exercise classes. All the assessments will take place at the Gait Laboratory of Queen Margaret University, Edinburgh. For the assessments, you will be asked to wear clothing that you normally wear during the exercise classes; also wear the splints you normally use; and bring with you any walking aid(s) that you use.

Each visit has four parts:
a) We will interview you and give you a workbook to take home.
b) We will record your physical fitness. This includes balance and the distance you can walk.
c) We will ask you to fill two questionnaires.
d) We will ask you to wear a small physical activity monitor at home.
We will now explain each of these parts in more detail below:

a) Interview
In the second visit, we will ask you about your goals for the exercise classes in the form of an interview. The goals which are decided will be documented in a workbook that you can take home. This workbook will help you to recall the goals. You can also record your progress in the workbook. With your consent, the agreed goals will be passed on to your exercise instructor so they can continue to work with you on your goals. In the following visits, we will ask you how far you have achieved the goals and will document it. Any new goals will also be recorded. In the last visit, we will interview you about your views on the goal setting program. With you permission, all the interviews will be audio taped using a digital voice recorder for analysis and quality assurance.

b) Tests of physical fitness:
We will ask you to walk for 10 metres, or if you can't walk this far, we will ask you to walk as far as you can. To assess your balance, we will ask you to stand up from your chair, walk 3 meters, then turn around, walk back and sit down. We will make every effort to minimise the risk of a stumble or fall. You may feel a little tired afterwards but the tests should not cause any pain or discomfort. We will give you adequate rest in between to make sure you do not get tired.

c) Questionnaires:
We will ask you to fill two questionnaires on your daily activities, mobility, memory, communication, quality of life and confidence.

Altogether, these assessments should take about two hours to perform.
You can bring a relative or friend or carer with you and ask for a break whenever you feel you need one

d) Physical activity monitoring:
Just before you go home, we will give you a small physical activity monitor (activPAL™, Fig. 1) that will record your activity (sitting/lying, standing and stepping) out with your exercise classes. You will need to attach it to your thigh of the stronger leg with sticky pads and wear it for 5 full days. We will show you how to attach it and also give you a sheet with all the instructions. The monitors are very small (size of a match box) and lightweight (20grams). You will need to remove the monitor during bathing and swimming as the monitor is not waterproof and put it back, once you finish.
We will ask you to post back your monitor after using it for 5 days in the stamped-addressed envelope which we will provide.

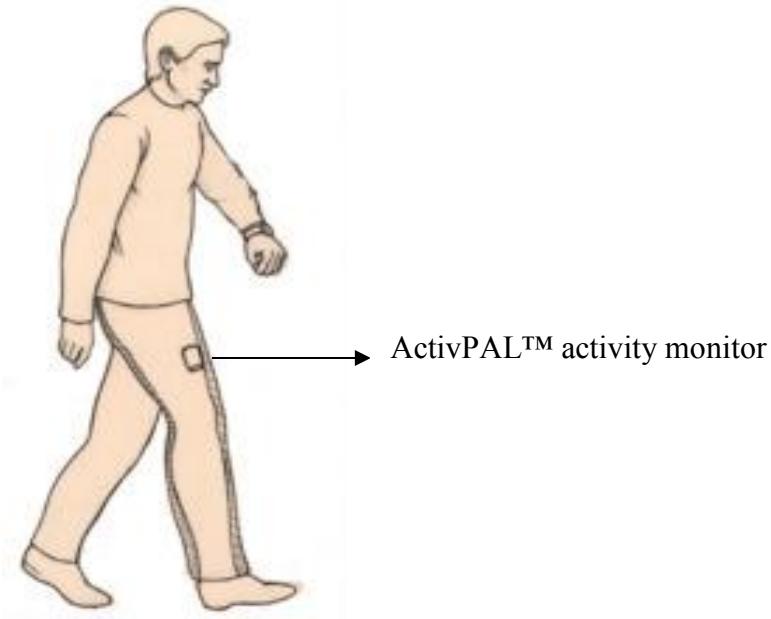
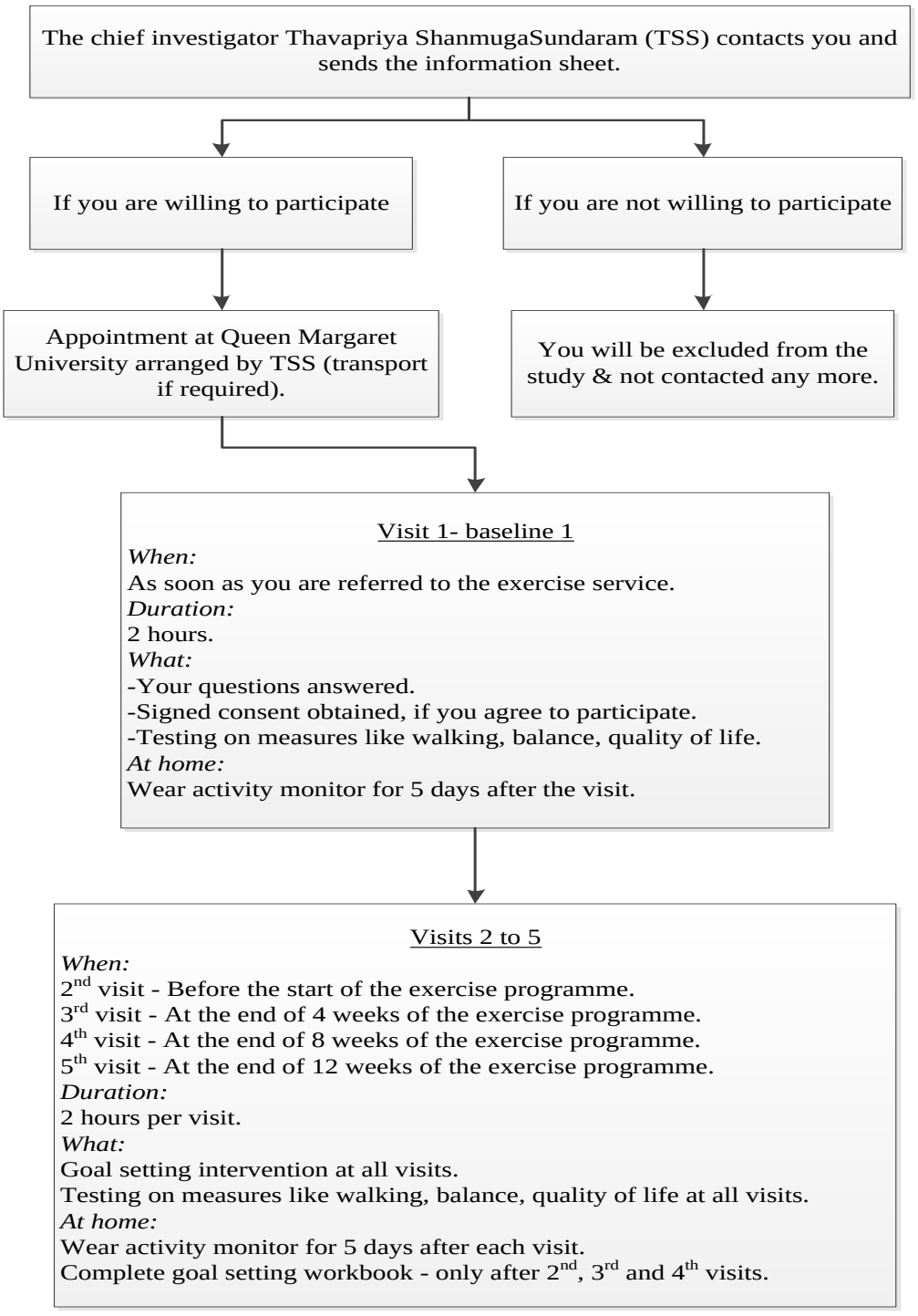


Figure 1. A person walking with activPAL™ activity monitor attached to the thigh.
(Source: http://www.paltech.plus.com/products.htm)

We recommend that you attend your exercise classes as usual.

The whole procedure is outlined as a chart below:



Expenses
Travel expenses to and from Queen Margaret University for you and for any person who accompanies you (carer, friend or relative) will be paid back to you.

What will I have to do?
You will be asked to wear the activity monitor as per the instructions and send it back after you have used it for 5 days. We will give you a full explanation and demonstration on how to apply the monitor. You can complete the goal setting workbook as you work towards your goals. We will give you a full explanation on how to do it.

What are the possible disadvantages and risks of taking part?
The study procedure is generally safe. Any minimal risk such as the possibility to fall, trip etc. has been minimised by undertaking a comprehensive risk assessment of the procedure and the site. The researcher conducting all the assessments is a trained Physiotherapist.

What are the possible benefits of taking part?
There may not be any direct benefit to you by taking part in this study, but the information we get from this project will help in identifying if formal goal setting methods are beneficial in the area of exercise after stroke. If effective, it could be introduced as part of an improved exercise service in the future.

What if there is a problem?
Any complaint about the study, the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information on this is given in part 2 of the information sheet.

This completes Part 1 of the information sheet.

If the information in Part 1 has interested you and you are considering in taking part, please continue to read the additional information in Part 2 before making any decision.

PART 2

What will happen if I don't want to carry on with the study?
You are free to withdraw from this study at any time, without giving a reason. If you agree, the data collected up to that point will be retained for use. If not, all previously collected data will be destroyed.

What will happen if I lose capacity at some point during the study?
If you agree, any data collected up to that point will be retained for use. If not, all previously collected data will be destroyed.

What if there is a problem?
Any complaint about the study, the way you have been dealt with during the study or any possible harm you might suffer due to negligence will be addressed. Queen Margaret University has a liability insurance scheme for compensation as a result of harm caused due to the negligence on the part of the researcher in connection with the above mentioned study but there are no compensation arrangements for non-negligent harm.

Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Once you have signed the consent form, a study participation number will be assigned to you and this number will be used throughout the research to maintain your confidentiality. All personal information collected will be kept strictly confidential. All hard copies of collected data will be stored securely in locked cabinets in Queen Margaret University while all electronic data will be stored in password protected computers in Queen Margaret University. Only the research team will have access to the data. Care will be taken through removing the names and addresses on any information presented, published or taken out of the premises for any reason.

Extracts from the interview may be used in the thesis and in any published material. However, no personal information will be revealed in any of this.

The data will be accessed only by researchers involved in the study. All the data collected will be kept for 5 years and will be then disposed of carefully.

The usual procedures for confidentiality, health and safety, and other research governance procedures operated by Queen Margaret University will be applied to this study. More details on QMU's research governance can be found on the following website: http://www.qmu.ac.uk/research_knowledge/ethics.htm.

Involvement of the General Practitioner/Family doctor (GP)
If you agree, your General Practitioner will be informed in writing about your participation in the study. If needed and only if you agree, we may also contact your GP to obtain further information on your medical condition.

Involvement of the exercise instructors
If you agree, the goals will be passed on to your exercise instructors so that they can help you work towards your goals.

What will happen to the results of the research study?
The results of the study will be published in the form of a thesis at Queen Margaret University as well as research papers in scientific journals and conferences. Care will be taken that the participants are not identifiable in any of the materials published.

Will I be informed about the results of the study?
Yes. Once the study is completed, a summary of the results will be mailed to your personal address.

Who is organising and funding the Research?
Queen Margaret University funds this study as a PhD degree. The study is conducted by Thavapriya ShanmugaSundaram, a research student of Queen Margaret University, Edinburgh.

Who has reviewed the study?
This study was given a favourable ethical opinion by the South East Scotland Research Ethics Committee 01.

Thank you for your time. If you have any questions, please contact Mrs. Thavapriya ShanmugaSundaram during office hours.

Contact Details:

Thavapriya ShanmugaSundaram
Research Student
Physiotherapy Subject Area
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 07989184486, 01314740000
E-mail: tshanmugasundaram@qmu.ac.uk

Dr. Cathy Bulley
Senior Lecturer
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: cbulley@qmu.ac.uk

If you would like to talk to an independent person who is not directly involved in the study, but who knows about the study, please contact Dr. Marietta van der Linden during office hours.

Independent Contact:

Dr. Marietta van der Linden
Research Fellow Physiotherapy
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: mvanderlinden@qmu.ac.uk

Queen Margaret University
EDINBURGH

Participant's Identification number: Study number:

CONSENT FORM

Title of the Project: **"Effects and experiences of goal setting for exercise after stroke**".

Name and address of the Researcher:

Thavapriya ShanmugaSundaram
Research Student, Physiotherapy Subject Area,
Queen Margaret University
Edinburgh EH21 6UU
Tel: 0131 474 0000
E-mail: tshanmugasundaram@qmu.ac.uk

Please initial box

I confirm that I have read and understood the information sheet (version 3, study 2, March 2012). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that I am under no obligation to take part in this study. ☐

I understand that I have the right to withdraw from this study at any stage without giving any reason. ☐

I understand that digital voice recorders will be used during the study and I agree to its use in this study. ☐

I understand that all the information will be used only for research purposes and that I will not be identified from it. ☐

In the event that I withdraw at some point, I agree to my data being retained up to that point. ☐

In the event that I lose capacity at some point, I agree to my data being retained up to that point. ☐

I agree to my GP being informed of my participation in the study. ☐

I agree to my GP being asked for more information on my medical condition. ☐

I agree to my exercise instructor at … being informed about the goals decided in this study. ☐

I agree to take part in this study. ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 13: Topic guide for interview on experiences of goal setting in study four

1. How did you feel about the goal-setting process?
2. Could you explain your role in the goal setting process?
3. Could you explain your thoughts on completing the goal setting workbook?
4. Would you be interested in doing goal setting in the future?

The answers to the above questions were considered and the following prompt questions were used to get more information.

1. Could you tell me more about that?
2. What do you mean by that?
3. Could you explain that further?
4. How do you feel about that?

Appendix 14: Ethical approval documents for study five

DIVISION OF DIETETICS, NUTRITION, BIOLOGICAL SCIENCES, PHYSIOTHERAPY, PODIATRY and RADIOGRAPHY

STUDENT PROJECT RELEASE FORM

This form is designed to notify each student of the DivREC response to individual Dissertation Proposals. A copy of the form will also be retained by the Committee to record each decision and to monitor resource requirements. *Students Please complete a – d below*

a. **PROJECT TITLE: ___ goal setting in exercise after stroke: perceptions of professionals_____**

b. **STUDENT(S): ____Thavapriya Shanmuga_____**

c. **SUPERVISOR: _____Cathy Bulley**

d. **SITE FOR DATA COLLECTION ____Glasgow_____**
(if not QMU state where)

e. **APPROXIMATE DATES FOR DATA COLLECTION: June – Sept 2012__**

All students should refer to Committee Response below and Comments overleaf

COMMITTEE RESPONSE

Decision	✓ / X	Date
1. Project proposal and Ethical approval granted	✓	**15/06/12**
2. Proceed with minor modifications to the project proposal (*as noted in response overleaf*)		
3. Resubmit revised proposal by		
4. Resubmit revised ethics by		
5. Submit for further ethics scrutiny (QMU / external)		
6. Project documentation incomplete		

Please note – you can not proceed to dissertation unless response box 1 or boxes 1 and 2 ticked ✓

GENERAL COMMENTS:

PLEASE NOTE: MINOR CHANGES TO PROPOSAL BE INFORMED TO DIVREC – MAJOR CHANGES MAY REQUIRE RESUBMISSION

This form will only be signed by Head of Division once project and ethical approval granted

Signature DiVREC member :_Gill Baer / Derek Santos_____ DATE__15/06/12_____

SIGNATURE OF HEAD OF DIVISION: ___Lynne Flynn____ DATE: _____

Submission 1 **Date __/__/__**

STUDENT TO COMPLETE sections i. – v. on submission			
ISSUES ADDRESSED	**Student complete this column**	**COMMITTEE RESPONSE**	**ACTION** (state whether for student / supervisor)
i. Subjects			
Number of subjects	**@30**		
QMU students or other? (Please state)	**other**	**Evidence of External approval / commitment to project**	
ii. Access to QMU facilities			
?which labs / rooms (if known)	**n/a**		
?when is access required (dates and/or times)	**n/a**		
iii. Training requirements			
Technician support required	**n/a**		
Supervisor to provide training	**n/a**		
iv. Equipment requirement			
state precise equipment requirements	**n/a**		
v. Costs			
(eg reprographics / postage / consumables)	**considered**		

DivREC representative to complete sections vi. – xv, after proposal scrutiny			
		RESPONSE	**ACTION REQUIRED**
vi.Recruitment Procedure (*any advert should be included by student)*	✓		
vii. Intervention / Investigation Procedure	✓		
viii. Outcome measures			
ix. Risk Assessment completed	✓		
x. Safety concerns (COSSH etc)	**nil**		
xi. Information sheet	✓		
xii. Consent Form	✓		
xiii. Independent advisor	✓		
xiv. Feasibility	✓		
xv. Other issues	**nil**		

Appendix 15: Participant information sheet and consent form for study five

Queen Margaret University
EDINBURGH

LETTER OF INVITATION

Date:

We would like to invite you to take part in the following research study.

Study Title:
Goal setting in exercise after stroke: perceptions of professionals.

Before you decide, you need to understand why the research is being done and what it would involve for you. Therefore, we have attached a detailed information sheet for you.

If you are willing to participate or would like to ask us any further questions regarding the study, please contact us using the contact details provided in the information sheet.

Thank you for your consideration.

With kind regards,

Thavapriya ShanmugaSundaram

Queen Margaret University
EDINBURGH

PARTICIPANT INFORMATION SHEET

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Goal setting in exercise after stroke: perceptions of professionals

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. If you have any questions, you can talk to us. Take your time to decide whether or not you wish to take part.

What is the purpose of the Study?
Exercise training is recommended for people affected by stroke, but improvements gained can be lost after some time. Goal setting with people affected by stroke may help to retain the improvements. We are interested in knowing whether this (goal setting) is used by professionals in exercise services, and how. We would also like to know more about how people feel about it. Studies have already explored the views of people with stroke, and health care professionals, but haven't explored the views and experiences of professionals involved in exercise services. We feel this important and could provide valuable information for service development. Therefore, we would like to explore the views and experiences of professionals involved in the exercise services regarding goal setting, by conducting focus groups.

Why have I been invited?
All Exercise Referral Scheme Advisors of … are being invited to take part in this study. You are being contacted by the Physical and Outdoor Activities Officer … on behalf of the researchers.

Do I have to take part?
It is entirely up to you to decide. Because of the timescales involved in the study, we would need to hear back from you within a week in order to include you in the study. If you decide to take part we will ask you to sign a consent form at the start of the focus group. You are free to withdraw from this study at any time, without giving a reason.

What will happen to me if I take part?
You will be involved in one focus group that lasts a maximum of 1.5 hours. The focus group will take place at a meeting room in …, at a date and time that will be arranged through discussion with participants. The group discussion will be moderated by 2 researchers from Queen Margaret University, Edinburgh. Their role will be to stimulate and focus the group's discussion around their perceptions of goal setting.

It is hoped that the group will discuss topics such as:

- Your views on goal setting;
- Any experiences of goal setting;
- Your opinions and suggestions relating to goal setting.

The group conversation will be recorded using digital voice recorders and digital video recorders. The verbatim will be transcribed from the voice recorders and be analysed by the researchers to identify and discuss the issues that the group raises.

What will I have to do?

All you have to do is to come to the focus group and speak about your views on goal setting. Everyone who attends will be asked to respect and keep confidential anything that is said by other participants during the focus group.

To help check whether our early analysis is valid, we will send you the key themes of group discussion around a week later and invite you to return any comments or corrections.

What are the possible disadvantages and risks of taking part?

We believe that the discussions would not move into any possible uncomfortable or upsetting situations.

What are the possible benefits of taking part?

There may not be any direct benefit to you by taking part in this study, but the information we get from this study could provide valuable information for service development.

What if there is a problem?

Any complaint about the study, or the way you have been dealt with during the study will be addressed. If you have a concern about any aspect of the study, you should ask to speak to the researchers who will do their best to answer your questions (contact details at the end). If you wish to speak to someone independent of the study you can contact Dr. Marietta van der Linden (contact details are provided at the end). If you still feel that your complaint has not been handled to your satisfaction you can contact the Registrar at Queen Margaret University.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

- Once you have signed the consent form, a pseudonym will be assigned to you and this name will be used throughout the research to maintain your confidentiality.
- The data available from the digital audio recorder will be transferred and stored in a password protected computer in Queen Margaret University. The files will then be immediately deleted from the audio recorder.

- The video recording will be used to help identify who is speaking for the transcription process, and then deleted.
- The transcripts of the verbatim will be anonymised - anything you say will be referred to with assigned pseudonyms.
- Care will be taken through removing the names and addresses on any information presented, published or taken out of the premises for any reason.
- Extracts from the discussion may be used in the thesis and in any published material. However, no personal information will be revealed in any of this.
- All personal information collected and consent forms will be kept strictly confidential by separate storage in a secured locked cabinet at Queen Margaret University. Only the research team will have access to this information.
- The transcripts will be stored securely in locked cabinets in Queen Margaret University. Only the research team will have access to this data.
- According to the Queen Margaret University's regulations, both the hard copies of data and electronic data will be retained for five years and will be then disposed of carefully.

The usual procedures for confidentiality, health and safety, and other research governance procedures operated by Queen Margaret University will be applied to this study. More details on QMU's research governance can be found on the following website: http://www.qmu.ac.uk/research_knowledge/ethics.htm.

What will happen to the results of the research study?
The results of the study will be published in the form of a thesis at Queen Margaret University as well as research papers in scientific journals and conferences. Care will be taken that the participants are not identifiable in any of the materials published.

Will I be informed about the results of the study?
A separate summary report will be produced and, if you wish, we will send a copy to your home address.

Who is organising and funding the Research?
Queen Margaret University funds this study as a PhD degree. The study is conducted by Thavapriya ShanmugaSundaram, a research student of Queen Margaret University, Edinburgh.

Who has reviewed the study?
This study was given a favourable ethical opinion by the Queen Margaret University ethics committee.

What should I do if I am interested in taking part?
If you would like to take part in this study, please complete the short form that is attached along with this letter. The form will ask for your personal details (including name, age, sex, contact details, qualifications, years/months in this current service, experience with participants with stroke) and a suitable time for the focus groups. Once

completed, please send it to the researcher in the enclosed self-addressed envelope. Based on your availability, we will contact you again to confirm the date, timings and venue of the focus groups.

Thank you for your time and consideration. If you have any questions, please contact Mrs. Thavapriya ShanmugaSundaram during office hours (contact details on next page).

Contact Details:

Thavapriya ShanmugaSundaram
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Physiotherapy Subject Area
Queen Margaret University
Edinburgh EH21 6UU.
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E-mail: tshanmugasundaram@qmu.ac.uk

Dr. Cathy Bulley
Senior Lecturer
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: cbulley@qmu.ac.uk

If you would like to talk to an independent person who is not directly involved in the study, but who knows about the study, please contact Dr. Marietta van der Linden during office hours.

Independent Contact:

Dr. Marietta van der Linden
Research Fellow Physiotherapy
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: mvanderlinden@qmu.ac.uk

Please note: For telephone contacts, Queen Margaret University has a voice operated system in use. So when telephoning, please ask for and speak to an operator who will connect you through to the person requested.

RESPONSE LETTER

Thank you for agreeing to take part in the study. Please complete the form below and send it to the researcher in the enclosed self-addressed envelope.

Name: _____
Age: _____
Sex: _____

Although this does not affect your ability to contribute to the focus group discussion, we are interested in your work role and hence, the following questions.
Job Title: _____
Qualifications: _____
_____
Number of years/months in this current job: _____
In your current job, have you worked with people who have had a stroke? _____

Contact Address (with contact phone number and email address):
_____
_____
_____
_____

Please indicate the most suitable method of communication: Phone / E-mail / Post

Please tick the days and times that would suit you to attend the focus group:

	AM (preferred time)	PM (preferred time)
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		

Please note below if you have any holidays booked until September 2012. This will help us to organise the focus group when you are available.
_____
_____
_____

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Why have I been invited?
All the Group Exercise Instructors of … are being invited to take part in this study. You are being contacted by …, on behalf of the researchers.

Do I have to take part?
It is entirely up to you to decide. Because of the timescales involved in the study, we would need to hear back from you within a week in order to include you in the study. If you decide to take part we will ask you to sign a consent form at the start of the focus group. You are free to withdraw from this study at any time, without giving a reason.

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To help check whether our early analysis is valid, we will send you the key themes of group discussion around a week later and invite you to return any comments or corrections.

Expenses

Travel expenses and the time spent in the discussion (1.5 hours) will be reimbursed.

What are the possible disadvantages and risks of taking part?

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name, age, sex, contact details, qualifications, years/months in this current service, experience with participants with stroke) and a suitable time for the focus groups. Once completed, please send it to the researcher in the enclosed self-addressed envelope. Based on your availability, we will contact you again to confirm the date, timings and venue of the focus groups.

Thank you for your time and consideration. If you have any questions, please contact Mrs. Thavapriya ShanmugaSundaram during office hours (contact details on next page).

Contact Details:

Thavapriya ShanmugaSundaram
Research Student
Physiotherapy Subject Area
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 07989184486, 01314740000
E-mail: tshanmugasundaram@qmu.ac.uk

Dr. Cathy Bulley
Senior Lecturer
School of Health Sciences
Queen Margaret University
Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: cbulley@qmu.ac.uk

If you would like to talk to an independent person who is not directly involved in the study, but who knows about the study, please contact Dr. Marietta van der Linden during office hours.

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Research Fellow Physiotherapy
School of Health Sciences
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Edinburgh EH21 6UU.
Tel: 0131 474 0000
E-mail: mvanderlinden@qmu.ac.uk

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Appendix 16: Topic guide developed and used in study five

Focus group with Referral Scheme Advisors

- Have you had experience of people with stroke attending your sessions?
- What has that been like?
  - What is the most challenging/interesting thing about people with stroke?
  - Is anything done differently for people with stroke?
  - Do you think your role is different when working with people who have had a stroke?
- What does the term 'goal setting' mean to you?
  - Are you familiar with it?
- How do you feel about goal setting in relation to your role?
  - Why?
- Is goal setting a part of your normal practice?
- How do you go about it? What is the process?
  - How do you decide whether to include goal setting or not?
  - Is it different with each participant?
  - How?
  - How would you describe the participant's role in this?
  - Do you keep a record of this goal setting?
- Is there anything challenging about goal setting?
  - How do you deal with it?
  - Any issues specific to goal setting with people who have had a stroke?
- When you've decided on goals, what happens next?
  - Do you pass on the discussed goals to the Group Exercise Instructors?
  - How?
  - Why?
  - Do you follow-up at all over time on how people are progressing with their goals?
- Do you think goal setting is/would be useful to the participants?
  - How?
  - Why?
- Have you felt supported in doing goal-setting?
  - How?
  - Why?
- Is there anything that might help?

Focus group with Group Exercise Instructors

- Have you had experience of people with stroke attending your class?
- What has that been like?
    - What is the most challenging/interesting thing about having people with stroke in the group class?
    - Is anything done differently for people with stroke?
- When you're running your classes, is there anything that you do specifically to try to motivate people to keep coming to the class?
    - Do you do anything differently for people with stroke?
- When you're running your classes, is there anything that you do specifically to try to motivate people to work harder in the class?
    - Do you do anything differently for people with stroke?
- What does the term 'goal setting' mean to you?
    - Are you familiar with it?
- Are you involved in goal-setting with participants in your classes?
    - How?
    - Why?
    - What is the process?
    - Is there anything about the process that is challenging?
    - How do you deal with that?
- Is there any difference between participants who come to the class directly and the participants who are referred through the Referral Scheme Advisors?
    - How does that work?
    - What happens next?
    - What do you do with that information?
- Do you think goal setting is/would be useful to the participants?
    - Why?
    - How?
- Do you think you could have a role in goal setting?
    - What type of role?
- Have you felt supported in doing goal-setting?
    - How?
    - Why?
- Is there anything that might help?

Appendix 17: Brief overview of the Transtheoretical Model of Change

The TTM is a 'stage-based' model that was proposed to understand the nature of behaviour change (Prochaska and Norcross 1994, Prochaska and DiClemente 1983). Constructs from several theories of psychotherapy and behaviour change were drawn upon in the construction of this model and hence the name Transtheoretical (Prochaska and Norcross 1994, Prochaska and DiClemente 1983). Although this model was initially proposed in the field of smoking cessation (Prochaska and DiClemente 1983), this framework is now increasingly being used to understand physical activity behaviour change (Biddle and Mutrie 2008, Prochaska and Marcus 1994). The TTM includes four constructs, namely the stages of change, processes of change, decisional balance, and self-efficacy (Prochaska and Norcross 1994, Prochaska and DiClemente 1983).

The Stages of Change is the most commonly used construct of the TTM. It represents a temporal dimension and is usually presented as six stages – precontemplation, contemplation, preparation, action, maintenance, and termination (Prochaska and Norcross 1994, Prochaska and DiClemente 1983). However, in relation to physical activity, which is the target behaviour in this programme of work, the sixth stage of termination is usually not considered (Biddle and Mutrie 2008). The definitions of the other five stages in relation to physical activity are presented in the table below. It is believed that movement between changes is cyclic and that individuals may move back and forth between stages before maintenance is reached (Prochaska and Marcus 1994).

Definitions of the Stages of Change in relation to physical activity

(Biddle and Mutrie 2008, Prochaska and Velicer 1997)

Key: * - for stroke survivors, the recommended physical activity is 20-40 minutes of continuous (or multiple sessions of ten minutes) moderate intensity aerobic training three to seven days a week (Gordon et al. 2004).

Stage	Definition
Precontemplation	Little or no physical activity, with no intention to change behaviour in the foreseeable future (usually defined as in the next six months).
Contemplation	Little or no physical activity, but with an intention to change in the next six months.
Preparation	Small changes in physical activity, with an intention to take action and improve physical activity in the immediate future.

Action	Specific overt modifications (i.e. regular physical activity*) made within the last six months.
Maintenance	Physically active for more than six months.

The processes of change are behavioural or experiential processes used by individuals to help them move between the stages of change (Prochaska and Velicer 1997). Ten processes have been highlighted within this theory, five of which are proposed as cognitive or 'thinking' strategies and five are described as behavioural or 'doing' strategies. These include: consciousness raising, dramatic relief, self-re-evaluation, environmental re-evaluation, self-liberation, social liberation, counter-conditioning, stimulus control, contingency management, and helping relationships (Prochaska and Velicer 1997). With regard to physical activity behaviour change, it has been demonstrated that individuals use all ten processes of change (Marshall and Biddle 2001). It was particularly highlighted that consciousness raising was important when moving from precontemplation to contemplation (Marshall and Biddle 2001).

The next construct within the TTM is decisional balance. How individuals' view the perceived benefits (pros) and risks (cons) is believed to reflect the stage of the change they are in (Prochaska and Velicer 1997). Empirical evidence suggests that the cons outweigh the pros in the early stages of change, while the reverse is true for the latter stages of change (Marshall and Biddle 2001).

The final construct of the TTM is self-efficacy, a concept borrowed from the SCT. Self-efficacy has been discussed in detail within the discussion of the SCT (refer to section 2.7.5.1 for a detailed explanation). Perceived low self-efficacy has been related to the lower stages of change (Prochaska and Velicer 1997).